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2nd edition

MEDICAL MANAGEMENT OF VULNERABLE AND UNDERSERVED PATIENTS

PRINCIPLES, PRACTICE, AND POPULATIONS

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Medical Management of Vulnerable and Underserved Patients

Principles, Practice, and Populations

Second Edition

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Preface

In the near decade since we published the first edition of this book, research has firmly established that populations of lower socioeconomic status and from minority racial and ethnic backgrounds have worse health and often receive a lower standard of health care. Worse health outcomes attributed to inequity in distribution of resources, initially termed disparities in health and health care, are now more aptly and pointedly referred to as inequities in health and health care. These inequities are attributed to broad social forces that shape the way we live and how medicine is practiced. With this perspective, a person's and a community's health and the health care they receive are measures of social justice.

As clinicians, there is perhaps no more distressing medical research than that which suggests that health-care workers and the health-care system contribute to inequities in health for vulnerable populations. Studies reveal that health-care workers continue to feel ill prepared when caring for vulnerable patients, especially those who are chronically ill, the elderly, addicted, mentally ill, victims of violence, or from minority or disadvantaged backgrounds. Hence, health-care workers may be the third factor in a "triple jeopardy" vulnerable patients face when it comes to health care: not only are these patients more likely to be ill and to have difficulty accessing care, but when they do, the care they receive is more likely to be suboptimal. Fortunately, training health-care workers to care for vulnerable patients makes a difference. With training, they are more willing to work with these populations and provide better care.

We hope the second edition of our book will be part of an ongoing process of improving our professions' ability to discharge its obligation to enhance social justice by both delivering comprehensive care for all patients and challenging the policies that undermine health for underprivileged patients and health-care access and delivery. Although grounded in health care as it is practiced in the United States, we draw from evidence and practices worldwide and believe that the concepts and approaches are relevant to medical practice globally.

The purpose of this book is to offer the theoretical background and practical knowledge required to teach clinicians to care for vulnerable, underserved patients both at the individual and system levels. In this book, we aim to illuminate the complexities of caring for vulnerable, underserved patients. We provide both an appreciation of the need to address inequities at multiple levels and practical suggestions for how to improve the care of vulnerable populations. We aim to "enable" health-care workers, students, and other interested parties to contribute to the solution. We focus on issues of patient care that are common among underserved patients and suggest ways to use our materials as teaching tools for health professions trainees in both didactic and clinical settings.

Our book is intended as a basis for teaching the core principles and skills required to care for our most complex patients—the vulnerable and underserved—where our clinical skills must be the most astute. Our text is appropriate for students, residents and practitioners (medical students, nurses, pharmacists, physician's assistants, public health, and other health-care practitioners) both in clinical, community, or social medicine classes and in practical experiences, including, but not limited to, primary care rotations and clerkships in family medicine, pediatrics, internal medicine, women's medicine, and psychiatry. As teaching hospitals are the major providers of care to uninsured, poor, and minority patients in the United States, the book is also intended as a resource for teachers and trainees who practice in these settings as well as public health-care settings internationally. Postgraduate trainees (e.g., residents and fellows) from all disciplines could use this text for didactics in behavioral and clinical medicine, and quality improvement. Finally, it can also serve as a rapid, yet comprehensive reference for all practitioners.

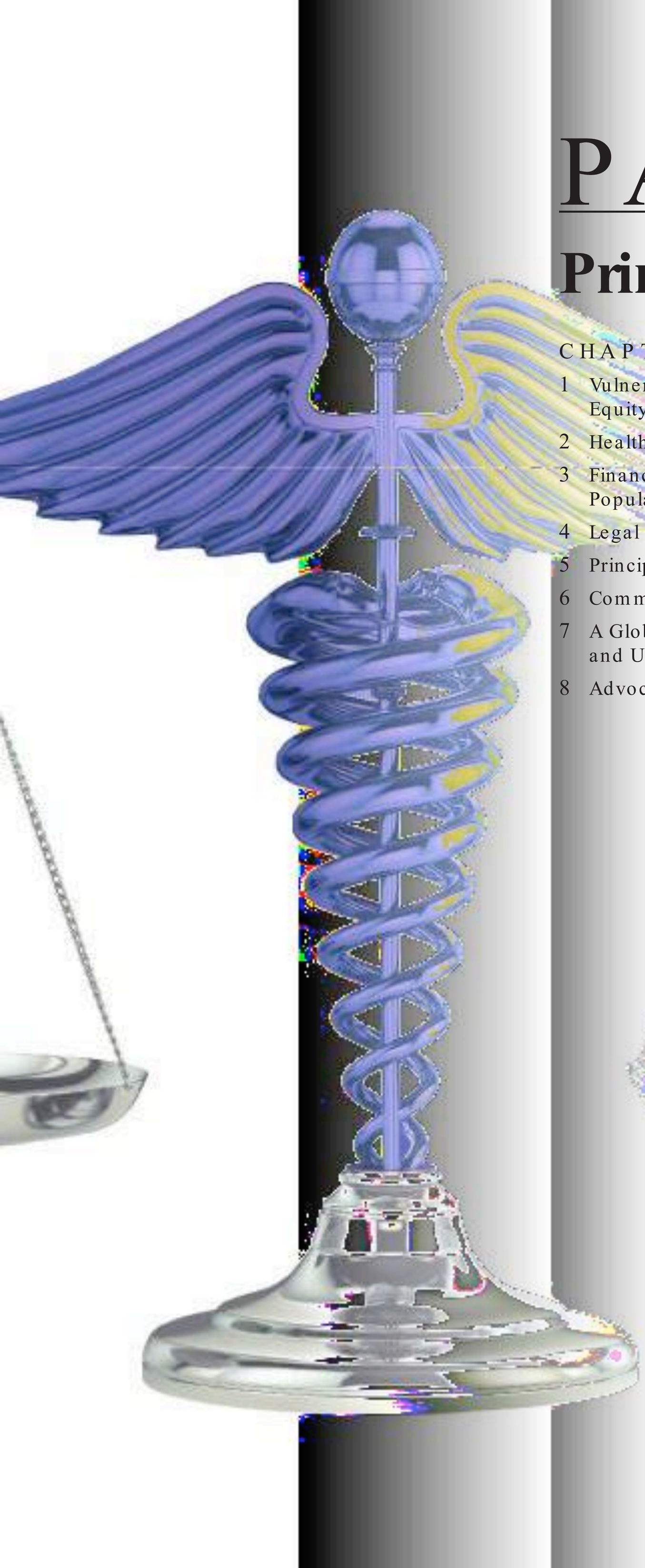
The book is organized into three sections: Principles, Practice, and Populations. Chapters in each section discuss ways in which both the individual practitioner and the health-care system may be more responsive to patients with these characteristics to assure they receive accessible, high-quality care, thereby reducing the inequities in health care that are both causes and consequences of vulnerability. We present clinical approaches to many issues that complicate caring for socially vulnerable patients. Many chapters feature both Key Concepts and Common Pitfalls, and end with a Core Competency highlighting important concepts and skills for quick and easy referencing.

Putting together a book of this scope and magnitude was no easy task and involved making certain decisions that not all readers may agree with. For example, while trying to keep the length of the book as manageable as possible, we were forced to exclude some relevant topics and decided to allow some overlap of content in those areas that are most critical. In addition, we welcomed differences of opinion among authors, provided the issues were clearly stated and the reasons for the author's opinion documented.

The first section, entitled Principles, lays out the theoretical groundwork of the book. Topics discussed include overview of the concepts of medical vulnerability and inequities in health and health care; financing and organization of health care for vulnerable populations; laws and regulations governing the care of medically underserved populations in the United States; and ethical dilemmas that arise in the clinical care of medically underserved populations. We also present chapters on engaging communities, on a global health-care perspective and promoting physician advocacy. The second section, Practice, considers overarching themes and skills necessary to care for patients. In particular, this section concentrates on population medicine and systems approaches to improving care to vulnerable patients. Topics discussed include the importance of building a therapeutic alliance and assessing for vulnerability; supporting health behavior change and adherence; principles of effective communication when cultural or literacy barriers may exist; models of care delivery to improve the effectiveness of medical care, such as the patient-centered medical home, group medical visits, and use of interactive health technologies; as well as quality improvement and case management programs. The third section, Populations, examines particular conditions or social circumstances that can lead to worse care. Chapters consider approaches to patients with histories of trauma, mental illness, intimate partner violence, and addiction, for example. Care of patients with limited English proficiency, history of incarceration, gay, lesbian and transgender patients, children, adolescents, and the elderly are subjects of others. In addition, this section addresses common situations that uniquely complicate the care of vulnerable populations such as environmental and occupational illnesses; the care of socially complicated hospitalized patients; end-of-life health care; chronic pain management; dental health; the care of patients with HIV/AIDS; and patients with disabilities. We end with a chapter that addresses the prevention of practitioner burnout.

We are deeply appreciative to the authors for their outstanding contributions to both editions of the book. Although the authors of some chapters have changed, we wish to acknowledge the influence and contribution of those who laid the foundation in the original chapters. We would also like to acknowledge the support and patience of the staff at McGraw-Hill. We especially wish to recognize the efforts of James Shanahan for believing in the project since its inception and to Amanda Fielding, Kim Davis, Laura Libretti, and Kritika Kaushik for bringing it to fruition. Finally, we are forever grateful to our patients for allowing us to participate in their care, our students for inspiring us to do better, and our families for their generous support.

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PART 1

Principles

CHAPTERS

1 Vulnerable Populations, Health Disparities, and Health Equity: An Overview

2 Health-Care Disparities: An Overview

3 Financing and Organization of Health Care for Vulnerable Populations

4 Legal Issues in the Care of Underserved Populations

5 Principles in the Ethical Care of Underserved Patients

6 Community Engagement and Partnership

7 A Global Perspective on the Care of Medically Vulnerable and Underserved Populations

8 Advocacy

Chapter 1

Vulnerable Populations, Health Disparities, and Health Equity: An Overview

Kevin Grumbach, MD, Paula Braveman, MD, MPH, Nancy Adler, PhD, and Andrew B. Bindman, MD

Objectives

- Define the terms vulnerable populations, health disparities, and health equity.
- Distinguish among differences in health, health disparities, and health-care disparities.
- Understand the relationship between social vulnerability and health disparities, and the pathways mediating this association.
- Recognize the ethical and human rights principles underlying efforts to achieve health equity
- Identify actions health professionals may take to change the social conditions that create vulnerability and produce health disparities.

INTRODUCTION

"Vulnerable" derives from the Latin word for wounded. Populations can be vulnerable for a variety of reasons. In this chapter, we focus on populations that are wounded by social forces that place them at a disadvantage with respect to their health. Vulnerability is visible in the variation across social groups in levels of resources and social influence and acceptance, as well as in the incidence, prevalence, severity, and consequences of health conditions.

This chapter provides an overview of the concept of vulnerability. It begins by introducing the notion of health disparities, distinguishing it from simple differences in health, and defining the closely related concept of health equity. It describes evidence of health disparities, particularly by socioeconomic status (SES) and race/ethnicity. It then discusses conceptual models for understanding the pathways between social vulnerability and poor health status. It concludes by suggesting that health professionals have a responsibility not only to develop their skills to respond effectively to the health-care needs of vulnerable patients but also to take action to change the fundamental social conditions that produce vulnerability.

WHAT ARE HEALTH AND HEALTH-CARE DISPARITIES?

Webster's dictionary defines disparity as a difference. "Difference" sounds like a neutral concept. It may seem logical that different people have different states of health, requiring different kinds and quantities of care. For example, elderly people are expected to be less healthy than young adults. People who ski are more likely to suffer leg fractures than people who do not.

Concern for health disparities is not about all differences in health, but rather about a subset of differences that are avoidable and suggest social injustice. Although few readers of this book probably were moved to righteous indignation by the health differences cited in the

example of skiers and more frequent broken bones, the following observations are likely to prompt qualitatively different reactions: A baby born to an African-American mother in the United States is more than twice as likely to die before reaching her or his first birthday as is a baby born to a white mother.[1] A World Bank study of 56 countries revealed that, overall and within virtually every country, infant and child mortality were highest among the poorest 20% of the population and lowest among the best-off 20% of the population; the disparities were large in absolute as well as relative terms.[2]

HEALTH DISPARITIES

"Health disparities" is a shorthand term denoting a specific kind of health difference between more and less privileged social groups. It refers to differences that adversely affect disadvantaged groups that are systematic and persistent, not random or occasional, and that are at least theoretically amenable to social intervention. The social groups being compared are differentiated by their underlying social position, that is, by their relative position in social hierarchies defined by wealth, power, and/or prestige; this includes socioeconomic, racial/ethnic, gender, and age groups and groups defined by disability, sexual orientation or identity, or other characteristics reflecting social privilege or acceptance.[3-5]

HEALTH-CARE DISPARITIES

Disparities in health care, as opposed to disparities in health, refer to systematic differences in health care received by people based on these same social characteristics. Although disparities in health care account for only a relatively small proportion of disparities in health, they are of particular importance to health-care providers and are discussed in detail in the next chapter.

HEALTH EQUITY

For individuals concerned about vulnerable and underserved populations, one overarching objective is eliminating health disparities. A slightly different way of framing this aspiration is to state that the goal is to achieve health equity. This frames the objective as a positive one (achieving equity) rather than a negative one (eliminating disparities). This approach mirrors defining health as a positive state of well-being and not just the absence of disease. Health equity may be understood as a desired state of social justice in the domain of health, and health disparities as the metric used to measure progress toward this state. A reduction in health disparities is evidence of making progress toward greater health equity.[6]

ROLE OF SOCIOECONOMIC CLASS AND RACE/ETHNICITY IN HEALTH DISPARITIES

Profound and pervasive disparities in health associated with a range of socioeconomic factors such as income or wealth, education, and occupation have repeatedly been documented in the United States and globally.[2,7-9] Despite ongoing debates about whether causation has been definitively established, considerable evidence has accumulated demonstrating, at a minimum, the biological plausibility of those associations.[10,11] Similarly, virtually wherever data on health according to race or ethnic group have been measured, racial or ethnic disparities in health also have often been observed; these disparities sometimes, but not always, have disappeared or been markedly reduced once socioeconomic and other contextual differences have been accounted for.[12-14]

SOCIOECONOMIC STATUS

Social class shows a strong association with health and longevity. Higher SES provides individuals with more material, psychological, and social resources, which can benefit their health. There is no standardized method for defining or measuring social class in the clinical setting, and this information is not routinely collected as a part of health-care encounters. Some of the typical dimensions of social class used in research studies include occupation, income, and education level, which are all components of what is generally referred to as socioeconomic status.

Some of the most compelling evidence about the association between SES and health comes from the Whitehall study in the United Kingdom. This research on British civil servants demonstrated a linear association of higher occupational grade with lower 10-year mortality.[15] This was a striking finding because significant differences in mortality occurred in a population in which all participants were employed and had health-care coverage. Despite the relative homogeneity of the group, those in higher occupational grades had significantly lower rates of a number of diseases as well as lower mortality. These differences remained 25 years later, even after some of the civil servants had retired from their jobs.[16] A similar SES and health gradient has been observed in the United States. A 2010 study using national data observed stepwise incremental gradients of health improving as either income or educational level rose, for scores of indicators across the life course.[8]

INCOME AND HEALTH

Analyses of the SES gradient generally reveal a sharp drop in mortality as income increases from the most extreme

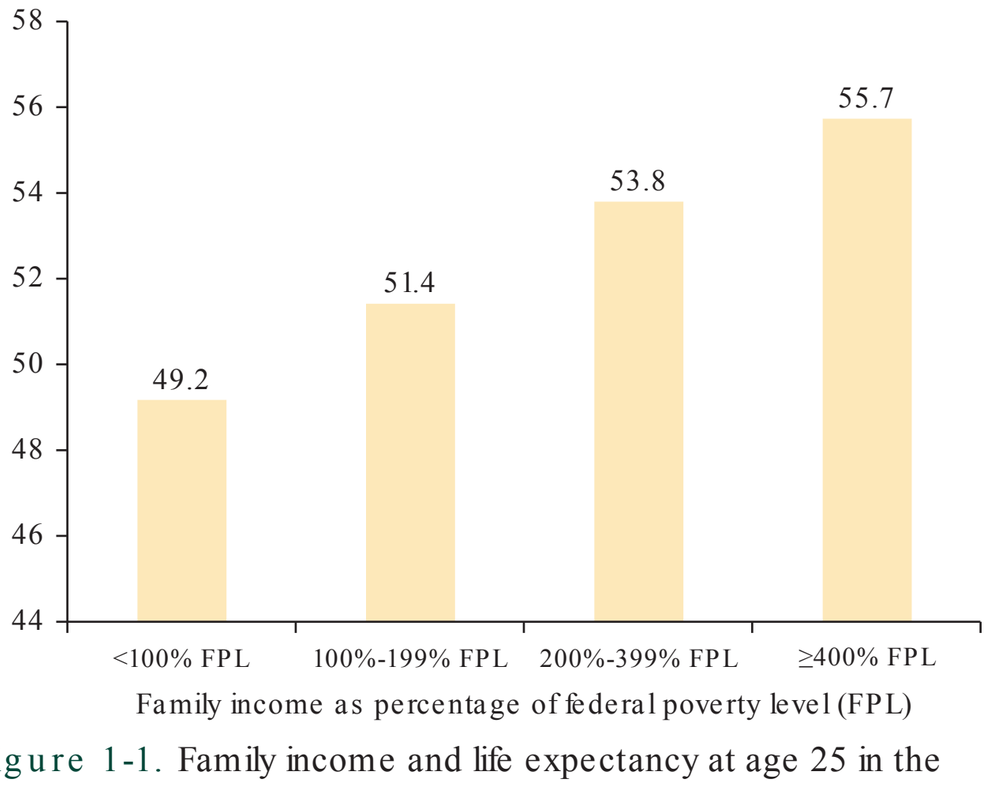


Figure 1-1. Family income and life expectancy at age 25 in the United States. This figure describes the number of years that adults in different income groups can expect to live beyond age 25. For example, a 25-year-old man with a family income below 100% of the federal poverty level can expect to live 49.2 additional years and reach an age of 74.2 years. (Source: CDC/NCHS, National Health Interview Survey Linked Mortality File, 2006. National Center for Health Statistics. Health, United States 2011: With Special Feature on Socioeconomic Status and Health. Hyattsville, MD: 2012. http://www.cdc.gov/nchs/data/hus/2011/fig32.pdf.)

categories of poverty toward more moderate poverty, and a continued but more gradual drop in mortality as incomes rises above this moderate poverty level. The National Longitudinal Mortality Survey in the United States showed a difference of more than 6 years of life expectancy at age 25, between those who were poor and those with incomes more than four times the poverty level; there was a 2-year difference in life expectancy at age 25 between those with intermediate-level incomes (200–399% of poverty) and the higher-income group (Figure 1-1).[8]

Above and beyond one's own economic status, there is some evidence that the distribution of income across a population makes a difference. Although still being debated, income inequality itself may be bad for people's health, irrespective of the average overall standard of living in a society. As discussed in Chapter 7, cross-national comparisons indicate that nations with less income inequality have better overall health indicators than nations at a comparable level of economic development with more unequal income distribution.[17]

Wealth is another measure of economic status. Wealth includes not just income, but also the value of assets such as home ownership, real estate, and investments—assets that often accumulate among families over generations. Wealth tends to have an even more inequitable distribution across a population than does income.

EDUCATION AND HEALTH

In contrast to the relationship between income and health, which demonstrates a continued drop in mortality

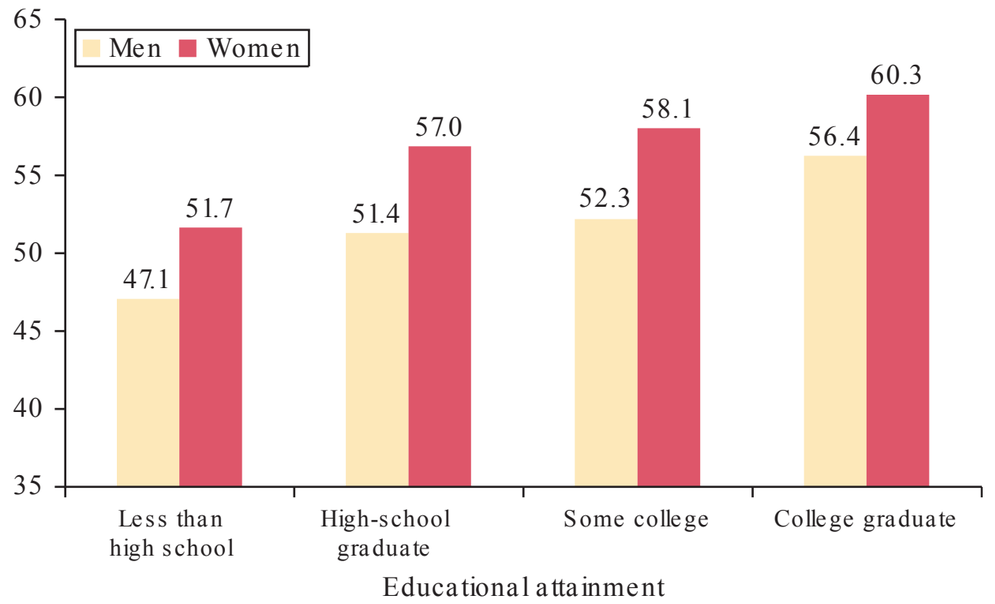


Figure 1-2. Educational attainment and life expectancy at age 25 in the United States. This figure describes the number of years that adults in different education groups can expect to live beyond age 25. For example, a 25-year-old man with a high school diploma can expect to live 51.4 additional years and reach an age of 76.4 years. (Source: CDC/NCHS, National Health Interview Survey Linked Mortality File, 2006. National Center for Health Statistics. Health, United States 2011: With Special Feature on Socioeconomic Status and Health. Hyattsville, MD: 2012. http://www.cdc.gov/nchs/data/hus/2011/fig32.pdf.)

as income increases (albeit with a sharper drop in the lower portion of the distribution), the association between mortality and education is more discontinuous. For all-cause mortality and each of the specific causes, the death rates are lower for those with more education (Figure 1-2). To the extent that education provides information, knowledge, and skills that improve health, each additional year of education should contribute somewhat equally to improved health. However, educational attainment also serves a credentialing function. As a result, there is a greater benefit of achieving years of schooling that result in a degree or credential than of additional years that do not. Thus, the benefit of completing the 12th year of schooling, which results in a high school degree, is greater than the benefit of completing any other single year of high school (referred to as the "sheepskin" effect).

The data linking education and health can more clearly be interpreted as a causal effect of education and health than is the case for income and health. While poor health can reduce one's income,[18] education occurs earlier in life than do most serious diseases, and this temporal ordering provides a strong rationale for attributing the association to the impact of education on health.

Data in the United States on SES and health have been limited. While public health monitoring and epidemiologic surveys frequently collect information on race and ethnicity, they less often include information on income or education. Until recently, death certificates had only data on race and ethnicity, but now include information on education but not occupation, income, wealth, or other SES variables.

RACE/ETHNICITY

Race and ethnicity often are combined and referred to as one concept. Nevertheless, the concept of race as commonly used tends to evoke differences in skin color and other superficial secondary characteristics, whereas ethnicity incorporates the concept of culture.[19]

The health implications of classification of both racial and ethnic groups derive primarily from the social construction and impact of being labeled as belonging to one or another group. Apart from a small number of genes that code for skin color and other superficial secondary characteristics, and a few genes that are linked to geographic origin which confer risk for specific diseases, there is little biologic basis for health disparities among racial and ethnic groups. Advances in genomics have exposed the concept of race as predominantly a social construct, rooted in historical biases and social stratification based on ancestry and superficial phenotype rather than emanating from fundamental genetic differences among populations perceived to be of different "races." There is no gene or set of genes that are exclusive to one race and that can be used to define those belonging to a race. Stated another way, one cannot look at a person's DNA and tell definitively that she or he is Asian, African American, Latino, or white. The genetic variation among people within a racial and ethnic group is much greater than the variation across groups.[20]

Despite the lack of definitive genetic determinants, race and ethnicity have important influences on health. Based on historical conventions, US federal agencies use a two-item approach to classification. The first item is considered to represent race, and includes five major groups: African American or black, American Indian or Alaska native, Asian, native Hawaiian or other Pacific Islander, and white. The second item is considered to measure ethnicity, and consists solely of a dichotomous categorization of Hispanic or non-Hispanic. In our view, such categorical distinctions between the concept of race and ethnicity are an oversimplification of this socially defined construct, and we use the term "race–ethnicity" to communicate a more holistic notion of this concept.

Disparities by race–ethnicity are present in the United States for such diverse health indicators as infant mortality, cancer mortality, coronary heart disease mortality, and the prevalence of diabetes, HIV infection, or stroke (Table 1-1). Two clear observations can be made about these health outcomes categorized by race and ethnicity. First, African Americans experience the greatest morbidity and mortality on every reported indicator, and the gap often is substantial. For example, African Americans experience 12.7 deaths for every 1000 live births, compared with Asian or Pacific Islanders, who experience 4.5 deaths. Second, no other group shows consistently poor health outcomes across all indicators. Whites show poorer outcomes than groups other than African Americans on many of the reported health indicators (e.g., overall cancer mortality). American Indians and Alaska natives have the second highest rates of infant mortality, and Hispanics or Latinos have the second highest prevalence of diabetes. Asian Americans and Pacific Islanders show the most favorable profile.

One limitation of these conclusions is that they are based on large groupings by race–ethnicity. These broad categories may obscure substantial variation in health within some of the groups. Members of the same major racial–ethnic group from different countries and areas of origin have different degrees of disadvantage and health risk. For example, among Latinos and Hispanics in the United States, the infant mortality rate is 4.9 among Cubans and 7.3 among Puerto Ricans. The importance of looking at subgroups also may differ by disease. For example, Asian Indians have the lowest rates of all-cause mortality, yet they have relatively high rates of coronary heart disease compared with other Asian groups.[21]

Table 1-1. Health Disparities by Condition and Race–Ethnicity

Health Condition and Specific Example	Race/Ethnicity				
	White	Black/African American	Hispanic/Latino	Asian and Pacific Islander	American Indian and Alaska Native
Infant mortality: rate per 1000 live births	5.5	12.7	5.6	4.5	8.4
Cancer mortality: rate per 100,000	173	206	120	108	158
Lung cancer mortality: rate per 100,000	49	52	21	25	40
Female breast cancer mortality: rate per 100,000	22	31	15	11	15
Coronary heart disease: mortality rate per 100,000	118	141	87	67	92
Stroke: mortality rate per 100,000	38	56	30	32	30
Homicides, per 100,000	2.6	19.9	6.6	2.2	9.0
HIV infection: prevalence per 100,000 adults	17	128	50	15	32
Diabetes: prevalence per 100 adults	6.8	11.3	11.5	10.2	DSU

DSU, data are statistically unreliable.
Source: CDC Health Disparities and Inequalities Report, United States, 2013. MMWR 2013;62(Suppl), No. 3; National Cancer Institute, SEER Cancer Statistics Review 1975–2011.

DUAL EFFECT OF SOCIOECONOMIC STATUS AND RACE/ETHNICITY

The overlap between race/ethnicity and SES makes it difficult to disentangle the relative contributions of each of these factors toward health.[22] Both African Americans and Hispanics are overrepresented in lower SES categories. Data from the 2010 census reveal that 30.3% of whites 25 years of age and older are college graduates, compared with 19.8% of African Americans and 13.9% of Hispanics. Similarly, there are large differences in income by race/ethnicity. For example, in 2009 the median family income was $38,409 for African Americans, whereas it was $62,545 for whites. If one uses a measure of net worth (wealth) instead of income, the economic differences by race/ethnicity are even more dramatic.

For some health outcomes, differences in the United States between African Americans and whites become much less significant once analyses control for income and/or education. For other health outcomes there continue to be differences associated with race/ethnicity that are not explained by socioeconomic class alone[23] (Figure 1-3).

The relative emphasis on disparities according to race–ethnicity and SES varies in nations across the globe, reflecting differences in both demographic characteristics and social history. A comparative analysis of US and EU approaches to health equity observed, "With a history marked by the legacy of slavery and discrimination, the United States has adopted a racially oriented perspective on certain social concerns to ensure equitable treatment under the law and safeguard civil rights. In Europe, by contrast, experience with ethnic group genocide during World War II has caused great reluctance to segment or even identify populations on racial or ethnic grounds. Consequently, authorities in many European countries have made a deliberate decision not to collect data on race and ethnicity."[24]

As social scientists continue to investigate the complex interplay among race–ethnicity, social statuses, and health status, the prevailing wisdom is that both race–ethnicity and SES matter.[7] Race–ethnicity can confer a vulnerability rooted in experiences of racism and social oppression that is not completely reducible to socioeconomic disadvantage. At the same time, focusing exclusively on disparities by racial and ethnic groups overlooks the contribution of socioeconomic inequalities to these disparities. The following section examines in detail the pathways through which social vulnerabilities such as minority race–ethnicity or low SES translate into poor health status.

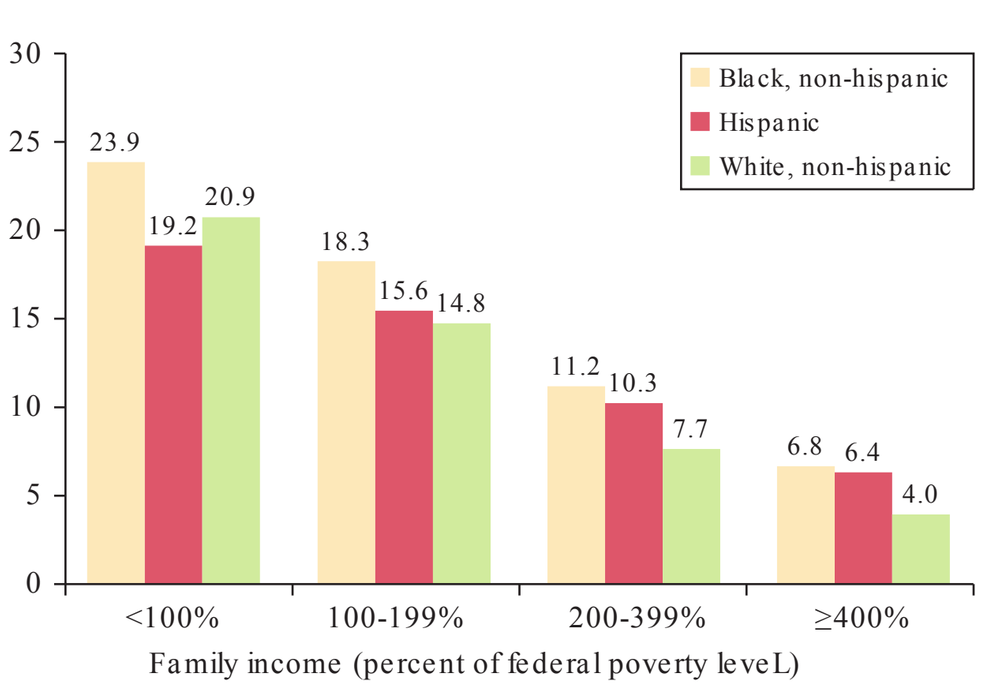


Figure 1-3. Self-rated health status according to race–ethnicity and income in the United States. (Source: CDC/NCHS, National Health Interview Survey 2010, Family Core and Sample Adult Questionnaire. National Center for Health Statistics. Health, United States 2011: With Special Feature on Socioeconomic Status and Health. Hyattsville, MD: 2012. www.cdc.gov/nchs/data/hus/2011/056.pdf.)

HEALTH DISPARITIES AND PATHWAYS OF VULNERABILITY

Phyllis Gripman has been driving a bus for 22 years. The stress of keeping on schedule despite traffic congestion and impatient commuters contributes to her poorly controlled blood pressure. She often skips taking her diuretic medication when working to avoid the need for bathroom stops, which could put her behind schedule. Frequently, passenger complaints about the bus service are coupled with derogatory comments about the fact that she is a woman and African American.

Tho Van fled his native Cambodia to escape the Pol Pot regime. He has nightmares reliving watching his brother being tortured to death. He often must rely on his daughter to translate during his medical visits. He avoids discussing his nightmares in front of his daughter. He worries about his teenage son, who has joined a gang and is truant from school.

Walter Jones has been homeless since his discharge from the army following the Iraq War. He has been in and out of rehabilitation programs for his heroin addiction. He is managing to stay clean while in a methadone maintenance program. He initiated evaluation for other medical problems at the Veteran's Administration medical center, but did not follow up for treatment after he overheard a physician refer to him as "that noncompliant homeless drug addict who's wasting our time and money."

These three examples identify individuals with social characteristics that make them vulnerable to experiencing health disparities. Viewed within the framework of health disparities, defined in the preceding as health differences between more and less privileged groups, "vulnerability" consists of those social characteristics, such as minority race–ethnicity and low SES, that are associated with health disparities. How do these characteristics ultimately result in inferior health status?

PATHWAYS BETWEEN DEMOGRAPHIC CHARACTERISTICS AND HEALTH STATUS

The conceptual model displayed in Figure 1-4 synthesizes ideas from a variety of models that have been proposed to explain the pathways between demographic characteristics and health status.[25-29]

This model proposes that poor health culminates from several major forces:

1. Genetic endowment and epigenetic processes. Everyone is born with a genetic endowment that offers relative protection against, or vulnerability to, certain conditions. Ms. Gripman, the bus driver, may have inherited a disposition to develop essential hypertension. Mr. Jones, the homeless veteran, may have a genetic susceptibility to opiates that abetted his addiction to heroin. However, health and illness are determined not just by one's genetic makeup but by "epigenetic" processes. Exposures and experiences across one's life can determine whether specific genes are activated or are suppressed. The occurrence of disease thus depends not just on the "hardwiring" of genetics but also on the "software" of epigenetics.
2. Physical environment. The air, water, food, toxins, and physical dangers to which one is exposed may have a profound impact on health. Minorities and the poor are more likely to reside in neighborhoods and work settings with unhealthful physical environments; therefore, this is a socially mediated influence on their health (see Chapter 25). For example, housing is often crowded, noise is pervasive, pollutants and toxins are prevalent, and facilities for exercise are sparse. Mr. Jones' lack of housing is a particularly glaring example of vulnerability in his physical environment.
3. Social environment. Vulnerable populations also often face an oppressive social environment, including factors such as institutional and other forms of racism, housing segregation, and low levels of social capital (generally defined as the resources that come from strong community and interpersonal relationships). Communities with greater social capital and collective efficacy (i.e., more able to organize and garner resources) have lower morbidity and mortality.[30,31] Mr. Van's experience of political violence and social disruption as a refugee from Cambodia poignantly represents a social environment that has adverse effects on health and the receipt of health care (see Chapter 29 and 36).
4. Behavior and lifestyle. Unhealthful behaviors such as smoking and substance use are more prevalent among people with less education, and sedentary lifestyles and high-fat diets are more common among African Americans and those with low SES.[32] The reasons for these high rates of prevalence are complex and also are heavily influenced by differences in physical and social environments, chronic stress, and delivery of health care (see Part 3: Populations).
5. Chronic stress. Researchers have begun to identify the toxic effects of chronic stress related to lack of economic and social resources or experiences of discrimination. McEwen[33] developed the concept of "allostatic load" to describe the biological processes involved in responses to chronic stress. Allostatic load scores have been found to be higher among African Americans than among whites and greater among those with less education.[34] Allostatic load scores, in turn, have been shown in a sample of older adults to predict physical and cognitive decline, the onset of new cardiovascular disease, and mortality over a 7-year period.[35,36] The types of occupational stresses experienced by Ms. Gripman have also been associated with unfavorable health outcomes.[37]
6. Health care. Inadequate access to and quality of health care is a final pathway to health disparities. Structural inequalities in the distribution of health-care resources, such as physicians and hospitals, across communities, may lead to inequity in access to and quality of care. The interpersonal process of delivering care may be deficient because of factors such as discrimination or lack of cultural or non-English language competence among health-care workers. For example, a clinic with greater availability of interpreters and culturally appropriate mental health services might afford Mr. Van greater opportunity for effective treatment of his posttraumatic stress disorder, resulting in better health status and well-being (see Chapters 14, 29, 31, 33).

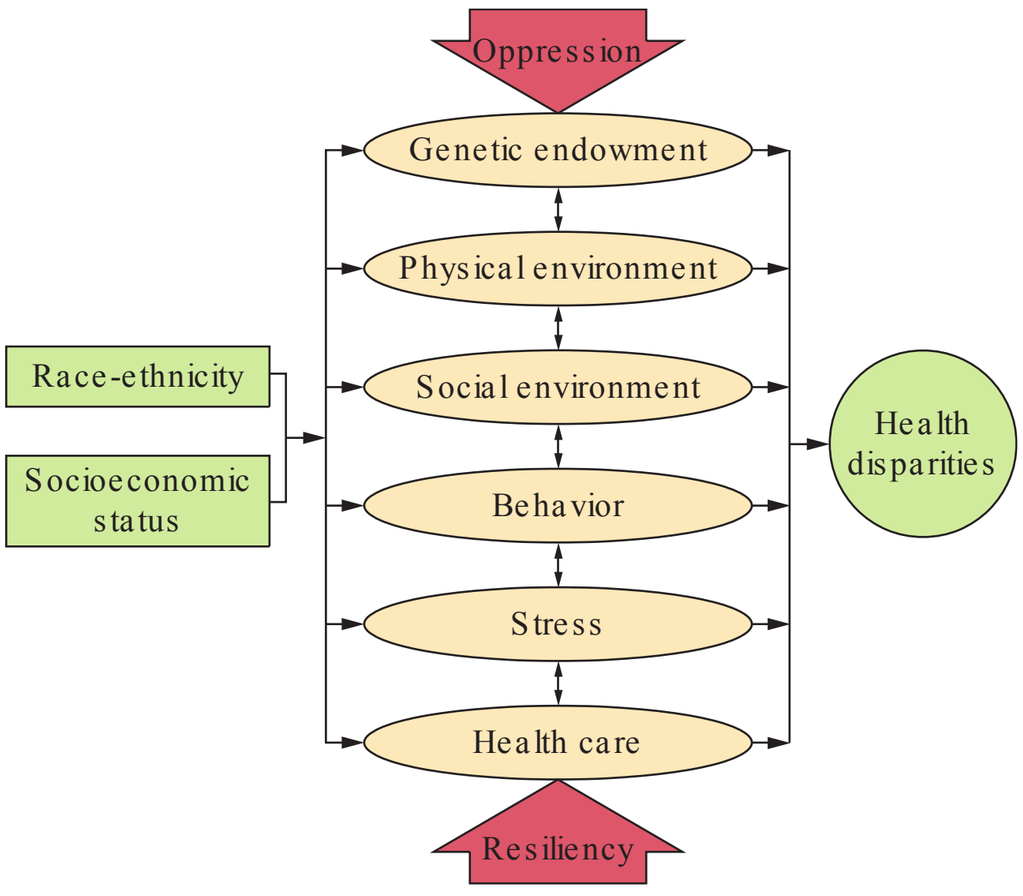


Figure 1-4. A conceptual model that synthesizes ideas from a variety of models proposed to explain the pathways between demographic characteristics and health status. This model proposes that poor health culminates from several major forces.

Although Figure 1-4 presents this model in a relatively linear form, it is important to recognize that the forces producing health disparities function in a more dynamic, multidirectional manner involving interactions and feedback loops among all the elements displayed. For example, chronic stress from war trauma may have contributed to Mr. Jones' adoption of unhealthful behaviors such as alcohol and drug use as a mechanism to cope with stress. Poor health or a chronic medical condition, such as Ms. Gripman's hypertension, may increase stress levels. Moreover, these factors all operate at multiple levels, ranging from the individual to the broader community and social institutions. The cumulative negative force of these pathways may be viewed as representing the social vulnerability that produces health disparities.

Most analyses have concluded that health care explains only about 10–20% of population health outcomes, with social, environmental, and behavioral factors being the most powerful determinants. As one leading public health advocate in the United States concluded about the powerful effect of social and environmental conditions, "Your ZIP code may be more important to your health than your genetic code."[38]

RESILIENCE

In contrast, individual and collective resilience—the capacity to develop positively despite harmful environments and experiences—represents the positive vector of these pathways that may act as a countervailing force and produce better health outcomes. One example of the positive effects that can result from individual and collective resiliency is reflected in the finding that first-generation immigrants appear to have a health advantage across virtually every group.[39] This may partially result from the "healthy immigrant" effect, in which there is differential selection for those who have the characteristics (including better health) that allow them to emigrate to the United States.[40] It may also reflect protective effects of traditional diets, supportive social networks, or other health practices of first-generation immigrants. The finding of lower mortality among older Mexican Americans living in neighborhoods with a higher density of Mexican Americans supports this view.[41] The researchers attributed this difference to the protective effects of the concentration, which may buffer Mexican Americans from the "unhealthful aspects of US culture."

ETHICAL AND HUMAN RIGHTS PRINCIPLES

Ethical and human rights principles underlie the notion of health equity. "Distributive justice," that is, normative ethical principles designed to allocate resources in limited supply relative to demand, is especially relevant to health disparities.[42]

DISTRIBUTIVE JUSTICE

The ethicist John Rawls has provided a framework for considering the principle of distributive justice and its application to health equity. In defining how one would know what was just an allocation of resources to different groups in a society, Rawls[43] introduced the notion of "the veil of ignorance." In his view, policies allocating resources should be made as if one were operating behind a "veil of ignorance" about the social group into which one had been born. If I did not know whether I would be born rich or poor, black or white, male or female, into a family living in a rural area or one in an urban area, how would I recommend allocating resources? Rawls believed that, under those circumstances, most people would prefer that resources be allocated according to need.

HUMAN RIGHTS AND THE RIGHT TO HEALTH

Human rights frameworks and principles provide a universally recognized frame of reference for initiatives to reduce health disparities between more and less advantaged social groups. When the term "human rights" is encountered, most people think of civil and political rights, such as freedom of speech and freedom from cruel or arbitrary punishment. However, human rights also encompass economic, social, and cultural rights, such as the right to a decent standard of living, which in turn includes rights to adequate food, water, shelter, and clothing requisite for health as well as the right to health itself.

Almost every country in the world has signed agreements that include health-related rights. The right to health is a cornerstone underlying efforts to achieve health equity. The World Health Organization's constitution[44] defined the right to health as the right of everyone to enjoy the highest possible level of health. The right to health can be operationalized as the right of all social groups (defined by social position) to attain the level of health enjoyed by the most privileged group in society. The right to health thus provides the basis for comparing the health experienced by different social groups, always using as the reference group the most privileged group in a given category.[4]

RACISM AND HEALTH

One final conceptual framework useful for understanding vulnerability derives from a model developed by Jones for understanding racism and its impact on health.[45] Jones proposes that racism operates at three levels: institutionalized, personally mediated, and internalized.

Institutionalized racism refers to the structural elements of racism that are "codified in our institutions of customs, practice and law so there need not be an identifiable perpetrator." Examples are housing segregation, school inequality, and the history of Jim Crow laws in the United States. Personally mediated racism is the prejudice and discrimination experienced in daily encounters, ranging from overt racial slurs to the less explicit racism of the prejudicial judgments made by teachers, clinicians, shopkeepers, and other social contacts. Internalized racism is defined as "acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth." Internalized racism manifests itself as lack of self-esteem and devaluing of the sense of self-worth. These types of racism may interact: for example, one study found that the impact of reported experiences of discrimination on risk of cardiovascular disease of African-American men was moderated by internalized racial group attitudes.[46]

Although developed for understanding racism, Jones' model is applicable to all the "-isms" that create social vulnerability. For example, the levels proposed by Jones apply to sexism. Sexism operates at an institutional level (e.g., objectification of women by mass media and entertainment, inadequate laws, and lax enforcement to protect women against violence and sexual abuse), interpersonal level (e.g., prejudice in hiring and promotion decisions), and internalized level (e.g., victimization, lowered expectations for achievement). The same principles apply to vulnerabilities based on social class, sexual orientation, gender identity, immigrant status, and other characteristics.[7]

TREATING VULNERABILITY: ADDRESSING THE ROOT CAUSES

For health professionals to successfully attend to the health needs of vulnerable populations, they must recognize how vulnerability manifests itself at each of these levels for each patient's particular constellation of vulnerabilities. Social consciousness is required to identify the factors that perpetuate vulnerability at the institutional level, whether in health-care organizations or other community institutions; to change these conditions requires translating awareness into social advocacy. Insight and reflection are necessary to enhance awareness of the biases and misassumptions—both obvious and subtle—that reinforce vulnerability at the personally mediated level. Finally, for clinicians to effectively care for vulnerable populations also require healing of patients' internalized wounds—the despair and devaluation of self-worth that thwart healthful living and healthy relationships.

What health-care providers can do to promote health equity by improving health care for socially vulnerable and underserved patients is addressed throughout this book. Subsequent chapters comprehensively discuss approaches to delivering more accessible, effective, and responsive health care and social services to vulnerable patients. However, the most effective treatment for the problems of vulnerable patients would be to change the fundamental social conditions that are the sources of vulnerability and primary determinants of health disparities.

Is it appropriate to expect health-care professionals to engage in arenas (e.g., health-care policy making) for which they are not trained? Without becoming policy makers themselves, health professionals have made major contributions to health-care policy debates by speaking out in diverse forums, contributing their time to support other activities of groups advocating for policies to reduce health-care disparities, and/or providing financial support for such groups.

At some time, nearly every health-care provider has experienced the frustration of providing an effective treatment for a patient's health problem, only to send the patient back to the same circumstances in the physical or social environment that caused or triggered the illness. An example is treating an asthma attack and then discharging the patient to the same substandard housing permeated with allergens. Virtually every clinician knows the frustration of prescribing regimens of medications, diet, and/or exercise to patients whose life circumstances make the successful implementation of those care plans very unlikely. For example, people who live in neighborhoods without stores that sell affordable fresh produce or in which outdoor exercise is unsafe or infeasible do not have the same opportunities to follow recommended regimens as those who live in more health-promoting neighborhoods.

However, most health-care professionals probably feel that fulfilling their own personal professional expectations as providers of high-quality health care, informed by the latest evidence, is difficult enough without adding expectations that they change their patients' life circumstances as well. In addition, health-care professionals feel ill equipped to change circumstances outside of the realm of health care that they are trained and experienced to provide. However, there are many feasible ways in which health-care providers can contribute to health equity, beyond their influence on reducing disparities in health care. Pragmatic strategies for engaging in advocacy to address social and environmental determinants of health are discussed in Chapter 8. Methods for integrating interventions to address social determinants into routine clinical practice are discussed in Chapter 9.

Health-care organizations as diverse as Kaiser Permanente in the United States and the Cuban National Health Service are finding common ground on a shared focus on the goal of population health, not just the health of individual patients. This focus is providing motivation and

incentives for health professionals to address the social and environmental determinants that influence the health of the populations they serve.

CONCLUSION

Patients like Ms. Gripman, Mr. Van, and Mr. Jones need excellent health professionals who understand the needs and circumstances of vulnerable populations and can deliver high-quality care to vulnerable patients. A public health perspective compels health professionals to not only heal the wounds of vulnerability but also eradicate the primary causes of those wounds. Health professionals committed to health equity do not need to become policy makers, or abandon health-care delivery, to make significant contributions to efforts to alter the fundamental conditions breeding vulnerability and producing health disparities.

KEY CONCEPTS

- Vulnerable populations are those with a disadvantaged position in social hierarchies defined by wealth, power, and/or prestige, placing them at risk for poor health.
- Health disparities are potentially avoidable, systematic differences in health status that are associated with social vulnerability and are at least theoretically amenable to social intervention.
- Several different pathways mediate the association between social vulnerability and health disparities, including genetic endowment, physical environment, social environment, behavior and lifestyle, chronic stress, and health care.
- Health equity refers to the absence of disparities in controllable or remediable aspects of health. A reduction in health disparities is evidence of making progress toward greater health equity.
- The ethical principle of distributive justice and international human rights principles provide a universally recognized frame of reference for initiatives to achieve health equity.
- In addition to promoting health equity by delivering high-quality health care to vulnerable populations, health professionals also can make meaningful contributions to improving the fundamental social conditions that create vulnerability and produce health disparities.

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DISCUSSION QUESTIONS

1. Review the data on health disparities shown in Table 1-1.
   a. What are some of the reasons that African Americans as a group have such poor health status relative to whites? Consider the different pathways mediating vulnerability and health status (e.g., social environment, physical environment) in suggesting the various mechanisms possibly mediating the association between African American race/ethnicity and poor health.
   b. The infant mortality rates for Latinos and non-Latino whites are nearly identical, despite Latinos as a group having much lower incomes and educational status than whites. What might be the factors that confer a "protective effect" for Latino birth outcomes and infant health in the face of socioeconomic disadvantage?
2. Many public health advocates call for the complete elimination of health disparities in the United States. Is this goal reasonable and feasible, or will societies always have inequities in health because of differences in income, education, occupation, and related aspects of SES among different members of a society?
3. Try to locate some data on public health measures in your own county, city, or community. (Your local or state health department may be a source of information comparing neighborhoods or social groups on health indicators such as infant mortality rates, age-adjusted mortality rates, cancer deaths, and preventable hospitalizations.) Use these data to identify a vulnerable social group (e.g., homeless persons, minorities) or a vulnerable neighborhood that appears to experience a health disparity. What are the most important factors in your local community contributing to this health disparity? Develop an action plan for how you and your colleagues could address these factors and improve the health of the identified vulnerable population. Make sure to consider interventions outside of the formal health-care system in developing your action plan.

RESOURCES

http://www.cdc.gov/omh/AboutUs/disparities.htm. Centers for Disease Control. Healthy People 2010: Goal of Eliminating Racial and Ethnic Health Disparities.

http://www.kaiseredu.org/topics_reflib.asp?id=329&parentid=67&rID=1. Kaiser Family Foundation. Race, Ethnicity and Health Care: The Basics.

http://www.macses.ucsf.edu/. MacArthur Foundation Research Network on Socioeconomic Status and Health.

http://www.sph.umich.edu/miih/index2.html. The Michigan Initiative on Inequalities in Health.

http://www.ucsf.edu/csdh/. The UCSF Center on Social Disparities in Health.

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Chapter 2

Health-Care Disparities: An Overview

Andrew B. Bindman, MD, Kevin Grumbach, MD, and Bruce Guthrie, MB, BChir, PhD

Objectives

- Define the term health-care disparities.
- Describe the patient and provider factors that influence access to and the use of health-care services.
- Review the characteristics of patients who are at increased risk for health-care disparities.
- Identify actions health professionals can take to promote equity in health care.

INTRODUCTION

The previous chapter defined health disparities as systematic, yet potentially modifiable, differences in health between more and less privileged social groups. This chapter focuses more narrowly on health-care disparities. After defining this term, the factors that contribute to health-care disparities, the patients affected by these inequities in access to and quality of care, and strategies to eliminate health-care disparities are discussed focusing on these issues in the US health-care setting.

QUALITY OF CARE AND HEALTH-CARE DISPARITIES

The Institute of Medicine has defined quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[1] Quality can be impaired in different ways, such as overuse, underuse, and misuse. There are major deficiencies on all of these accounts in the quality of care provided by the US health-care system. For example, there are major deficiencies in the quality of care provided to patients with common chronic diseases: two-thirds of patients with high blood pressure are inadequately treated; the majority of patients with diabetes have glycohemoglobin (A_{1C}) levels >7%; and half of the patients hospitalized with congestive heart failure are readmitted within 90 days of discharge.

Furthermore, many studies have shown that social status can contribute to the quality of care a patient receives. Social status may alter health-care professionals' perceptions of patients' needs or the way in which patients interact with health services and this in turn may influence the quality of care that is received. In the United States, for example, patients from racial and ethnic minority groups as compared with white patients experience more frequent barriers to care, more limited treatment options when presenting for care, and greater deficits in the quality of care. Such health-care disparities are seen in association with measures of social status throughout the world. For example, in the United Kingdom, quality of care for patients with diabetes is positively associated with income.[2]

These health-care inequities reflect systematic differences in access to or quality of care between more and less privileged groups that cannot be explained by the

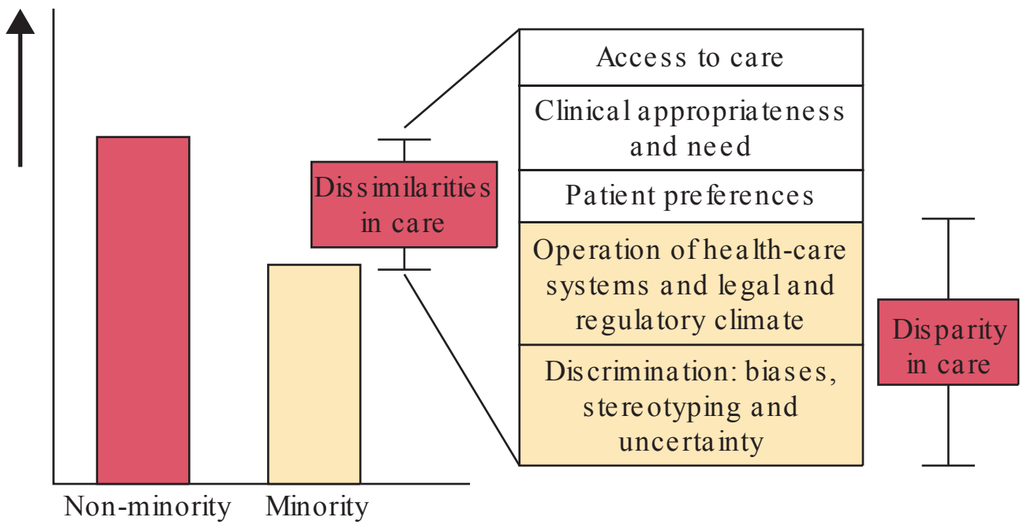


Figure 2-1. Model of health-care disparities. The Gomes and McGuire model views health-care disparities as resulting from characteristics of the health-care system, the society's legal and regulatory climate, discrimination, bias, stereotyping, and uncertainty. Not all dissimilarities in care are considered a disparity in care. (Adapted from Gomes C, McGuire T. Identifying the sources of racial and ethnic disparities in health-care use. Boston, MA: Department of Health Care Policy, Harvard Medical School, 2001. Cited in Smedley BA, Stith A, Nelson A, eds. Unequal treatment: Confronting racial and ethnic disparities in health care. Washington, DC: National Academy Press; LaVeist TA, Isaac L. Examples of Racial Disparities in Health Care. Baltimore, MD, 2005.)

differences in the need for care or preference for care among the individuals in these groups (Figure 2-1).

MEASURES OF QUALITY: PROCESSES OR OUTCOMES OF CARE

> William Mason and Peter Dixon are admitted to the same hospital on the same day with the same diagnosis: ST wave elevation myocardial infarction (STEMI). Mr. Mason, a white business executive, is promptly rushed to the cardiac catheterization suite where he receives coronary angioplasty and stenting. He is discharged home on aspirin, clopidogrel, a statin, a beta-blocker, and an angiotensin-converting enzyme inhibitor. Three months later, he is able to garden without experiencing angina. Mr. Dixon, an African American who is an intermittently employed construction worker, is admitted to the coronary care unit but does not receive a coronary arteriogram during his hospital stay. He is discharged home on a statin and calcium channel blocker. Two weeks later, he is readmitted with unstable angina.

Applying a quality-of-care framework developed by Donabedian, health-care disparities can be observed to occur in the processes or outcomes of care.[3] Processes of care are the actions health-care providers take to diagnose, treat, and manage patients' health-care needs. Health outcomes, such as morbidity and mortality, are, in part, consequences of these health-care actions.

> Mr. Mason had a process of care that was more consistent with evidence-based guidelines than the care received by Mr. Dixon. The inferior process of care received by Mr. Dixon contributed to him having a worse clinical outcome (recurrence of symptomatic coronary heart disease) than Mr. Mason. Of particular concern are the types of health-care disparities illustrated in this case that contribute to inequities in health outcomes (health disparities).

Most investigators agree that health-care processes have a relatively modest role in explaining health disparities—perhaps explaining only 10–20% of the variation in health outcomes among different groups.[4] On the other hand, health disparities resulting from health-care disparities clearly are in the purview of the people working in the health-care system and are amenable to change. Health professionals have a particular obligation to eliminate disparities in access to and quality of care that contribute to health inequity for vulnerable populations.

BEHAVIORAL MODEL APPLIED TO HEALTH-CARE DISPARITIES

Why is a patient like Mr. Dixon less likely than a patient like Mr. Mason to receive high-quality care? One of the most frequently used models for conceptualizing access to care is the behavioral model developed to explain differences in care received by different people or groups of people.[5] The behavioral model proposes analyzing the care people receive by looking at three fundamental categories of factors: need, predisposing characteristics, and enabling resources. Gelberg and colleagues have revised the model based on their work with homeless populations, proposing a behavioral model for vulnerable populations that includes both traditional categories and vulnerable domains (Table 2-1).[6]

NEED FOR CARE

It is axiomatic that people with a greater need for health care, all other things being equal, make greater use of health-care services. For example, a patient with diabetes has a greater than average need for health care. How much need depends on the severity of the diabetes, and whether there are complications or other chronic conditions. Having diabetes per se does not necessarily constitute a disparities-related vulnerability (although it is certainly a risk factor for adverse health outcomes such as heart disease and kidney failure). On the other hand, some clinical conditions may in and of themselves confer a social vulnerability. Prime examples are the socially stigmatizing conditions of learning disabilities, mental illness, and substance use, where the conditions themselves can alter the presentation of illness and where health professionals' perceptions can contribute to inadequate care.

Table 2-1. The Behavioral Model Applied to Vulnerable Populations

Traditional Domains	Vulnerable Domains
Need	
Perceived health • General population health conditions Evaluated health • General population health conditions	Perceived health • Vulnerable population health conditions Evaluated health • Vulnerable population health conditions
Predisposing Characteristics	
Demographics • Age • Gender • Marital status • Veteran status Health beliefs • Values concerning health and illness • Attitudes toward health services • Knowledge about disease Social structure • Ethnicity • Education • Employment • Social networks • Occupation • Family size • Religion	Social structure • Country of birth • Acculturation/Immigration/ Literacy • Sexual orientation • Childhood characteristics • Residential history/ Homelessness • Living conditions • Mobility • Length of time in the community • Criminal behavior/Prison history • Victimization • Mental illness • Psychological resources • Substance abuse
Enabling Resources	
Personal/Family resources • Regular source of care • Insurance • Income • Social support • Perceived barriers to care Community resources • Residence • Region • Health services resources	Personal/Family Resources • Competing needs • Hunger • Public benefits • Self-help skills • Ability to negotiate system • Case manager/Conservator • Transportation • Telephone • Information sources Community resources • Crime rates • Social services resources

Source: Gelberg L, Andersen RM, Leake BD. The behavioral model for vulnerable populations: Application to medical care use and outcomes for homeless people. Health Serv Res 2000;34:1273-1302.

In the preceding case, might there have been some difference between Mr. Dixon's clinical presentation that made it appear that Mr. Dixon had less clinical need for urgent coronary stenting?

PREDISPOSING CHARACTERISTICS

Predisposing characteristics refer to health beliefs and culture, care-seeking behaviors, trust in health care and other social institutions, and related characteristics that may influence whether, when, and from whom an individual decides to obtain health care when needed. Health education may assist individuals to make well-informed decisions about using health-care services.

Patients from vulnerable groups such as ethnic minorities may understandably be less trusting of the health-care system because of personal or collective experiences of social injustice in that setting. One glaring example of this is the Tuskegee Syphilis Experiment.[7] Between 1932 and 1972, the US Public Health Service conducted an unethical study at the Tuskegee Institute in Alabama in which African-American patients with syphilis were left untreated in order to observe the "natural" progression of syphilis—despite the discovery in the 1940s of penicillin as a highly effective treatment for this infection. African Americans cite the Tuskegee experiment as one reason for concern that medical research may exploit rather than aid them.[8] Personal experience of racism contributes even more significantly to mistrust of medical care.[9]

The human resources deployed in the health-care system also may contribute to vulnerable patients' mistrust of the health-care system and predisposition against using health-care services. Physicians tend to come from backgrounds that are more privileged and, by virtue of their occupation and income, have a socioeconomic status that on average is higher than that of the population of patients they serve. In the United Kingdom, nearly 60% of medical students come from families in the top 20% of income distribution.[10] This can contribute to a sense of social distance between physicians and patients. In addition, the ethnic and cultural backgrounds of many health professionals are different from the characteristics of patients who seek their services. African Americans, Latinos, and Native Americans are underrepresented within the health professional workforce. These three minority groups comprised 26.6% of the US population 16 years and older during 2008–2010, but contributed only 11.3% of the physicians, 17.2% of physician assistants, 15.1% of the registered nurses, 9.0% of the dentists, and 9.8% of pharmacists in the United States.[11] African-American patients cared for by African-American physicians report that their physicians include them more in medical decision making and that they are more satisfied with their care than those who are cared for by non–African-American physicians.[12] Similarly, Spanish-speaking patients are more satisfied with the care they receive from Spanish-speaking physicians.[13] In the United Kingdom, South Asian patients report higher enablement after consultations with physicians with whom they share a language.[14]

> Is it possible that both Mr. Mason and Mr. Dixon were offered urgent cardiac catheterization by their physicians, but Mr. Dixon might have declined to have the procedure performed because of less trust in his physicians and nurses?

ENABLING RESOURCES

Enabling resources are factors that promote access to effective health care. These resources may be at the community or personal level. Community-level enabling resources are the assets of the local health-care system and other social services. The presence of a community clinic that provides financial assistance for low-income patients or has interpreters on site are enabling resources that contribute to improving access to care, particularly in low-income and minority communities where private physicians are less likely to practice.[15] The access to care barriers associated with the scarcity of physicians in certain communities can be compounded by the lack of another community "enabler," reliable transportation.

Among the most obvious and fundamental resources that make care easier for a person to access are financial resources: health insurance and the financial means to pay for those health-care costs not covered by insurance. Lack of health insurance is the single greatest impediment to access to care in the United States and results in unnecessary morbidity for affected individuals and inefficient use of health-care resources.[16] Numerous studies have demonstrated that the uninsured are less likely than those with health insurance to have a regular source of health care, have fewer physician visits, are less likely to receive appropriate preventive services, and are more likely to delay receiving needed medical care. The uninsured are 30% to 50% more likely than privately insured persons to have some deterioration in their health resulting from a chronic condition such as diabetes or asthma that ultimately necessitates a hospitalization that could have been prevented with timely ambulatory care.[17]

Other research has demonstrated that the uninsured present for care with more advanced stages of cancer, including breast, colorectal, prostate, and skin cancers. Delay in diagnosis is one of the reasons that the uninsured have shorter life expectancies than insured persons. The Institute of Medicine estimates that the age-specific mortality rate is 25% higher in the uninsured than in the privately insured population.[18]

Not surprisingly, socioeconomic class is a strong predictor of health insurance status. Although 80% of the uninsured live in families with a working adult, the majority of uninsured persons have family incomes falling at the lower end of the income scale. Without financial assistance, these individuals have a limited ability to purchase health insurance coverage and few personal financial resources to allow them to overcome barriers to care associated with the lack of health insurance.

Until the passage of the Patient Protection and Affordable Care Act (ACA) in 2010 and its implementation in 2014, many low-income individuals were eligible only for public coverage on an emergency basis through Medicaid when they became so ill that they required hospitalization. Patients with a chronic disease who only have episodic health insurance coverage for hospitalizations are less likely than those with continuous coverage to receive appropriate treatment in the ambulatory setting that could prevent the pain and suffering associated with complications of their illness.[19] The impact of this is apparent in cross-national comparisons with countries that have universal health insurance coverage. For example, the United States has greater disparities in hypertension control across socioeconomic groups than the United Kingdom where health insurance coverage is universal.[20]

Individuals from racial and ethnic minority groups are more likely than whites to be uninsured, a situation that contributes to racial and ethnic disparities in health care. In 2012, prior to the full implementation of the ACA in the United States, 29% of Latinos, 19% of African Americans, 15% of Asians, and 11% of non-Latino whites were uninsured.[21] Variations in average income between racial and ethnic groups explain much, but not all, of the differences in rates of health insurance by race and ethnicity.

> Might it have been the case that Mr. Dixon was uninsured, and that is why his physicians did not provide the same resource-intensive care received by Mr. Mason?

HEALTH-CARE DISPARITIES: THE EVIDENCE

As discussed in Chapter 1, race/ethnicity and socioeconomic status are powerful predictors of a person's health status. These same factors are also strongly associated with access to health care and quality of care. There is ample evidence indicating that the differences in care received by Mr. Mason, a high-income white man, and Mr. Dixon, a working-class African-American man, are indicative of pervasive differences in processes of care in the United States based on race/ethnicity and class. Reported disparities in care related to income are worse in the United States than in countries that provide universal health insurance coverage.[22] Disparities in health care associated with race and ethnicity are less well documented outside of the United States, making it difficult to compare deficiencies in quality by race and ethnicity in the United States with those that may be present in other countries.

RACE/ETHNICITY

Individuals from minority groups are less likely than whites to have a regular source of care or to have had a doctor visit in the past year. Minorities are also more likely to report delays in receiving needed care. Summarizing a series of national access to care indicators, the Agency for Health Research and Quality determined that access to care is generally better for non-Latino whites than for members of all other racial and ethnic groups in the United States. The Agency found that when compared with whites on measures of access to care, Latinos scored worse on 62%, Native Americans on 43%, African Americans on 33% and Asians on 24%.[23] Even more concerning is the finding that between 2000–2002 and 2010–2011, the number of access measures in which disparities by race and ethnicity improved over time was small. As compared with non-Latino whites, Latinos improved on 3 and declined on 1 of 14 measures. There were no relative improvements or declines for Native Americans over time. African Americans had 1 of 14 access measures and Asians had 2 of 12 access measures improve relative to those for non-Latino whites.

The National Healthcare Disparities Report applied quality indicators for preventive, prenatal, neonatal, cancer, and cardiac care, as well as care for chronic conditions such as diabetes, asthma, and HIV/AIDS—measures that extend beyond more general indicators of access to care (e.g., ability to obtain medical care when needed) to assess whether patients received specific services appropriate to their medical needs (Figure 2-2). Results indicate that in 2010–2011, African Americans received poorer quality of care than whites for more than 40% of the measures. Latinos and Native Americans were also less likely than non-Latino whites to receive a high quality of care. The reasons for these differences remain ill defined, but it has been shown that the US health-care system's organization contributes to inequities in health care. For example, minority patients commonly receive care concentrated within a relatively small group of physicians who report that they do not have access to the full range of clinical resources needed to provide quality care.[24]

HEALTH INSURANCE

Do these differences in health care according to race/ethnicity simply reflect the fact that minorities are less likely than whites to have private health insurance? Indeed, differences in access to and quality of care are partly attributable to differences in their health insurance status; however, these differences persist even among individuals with the same type of insurance coverage. For example, within Medicare, a public health insurance program for the elderly that is designed to provide a uniform benefit to its beneficiaries, non-whites have

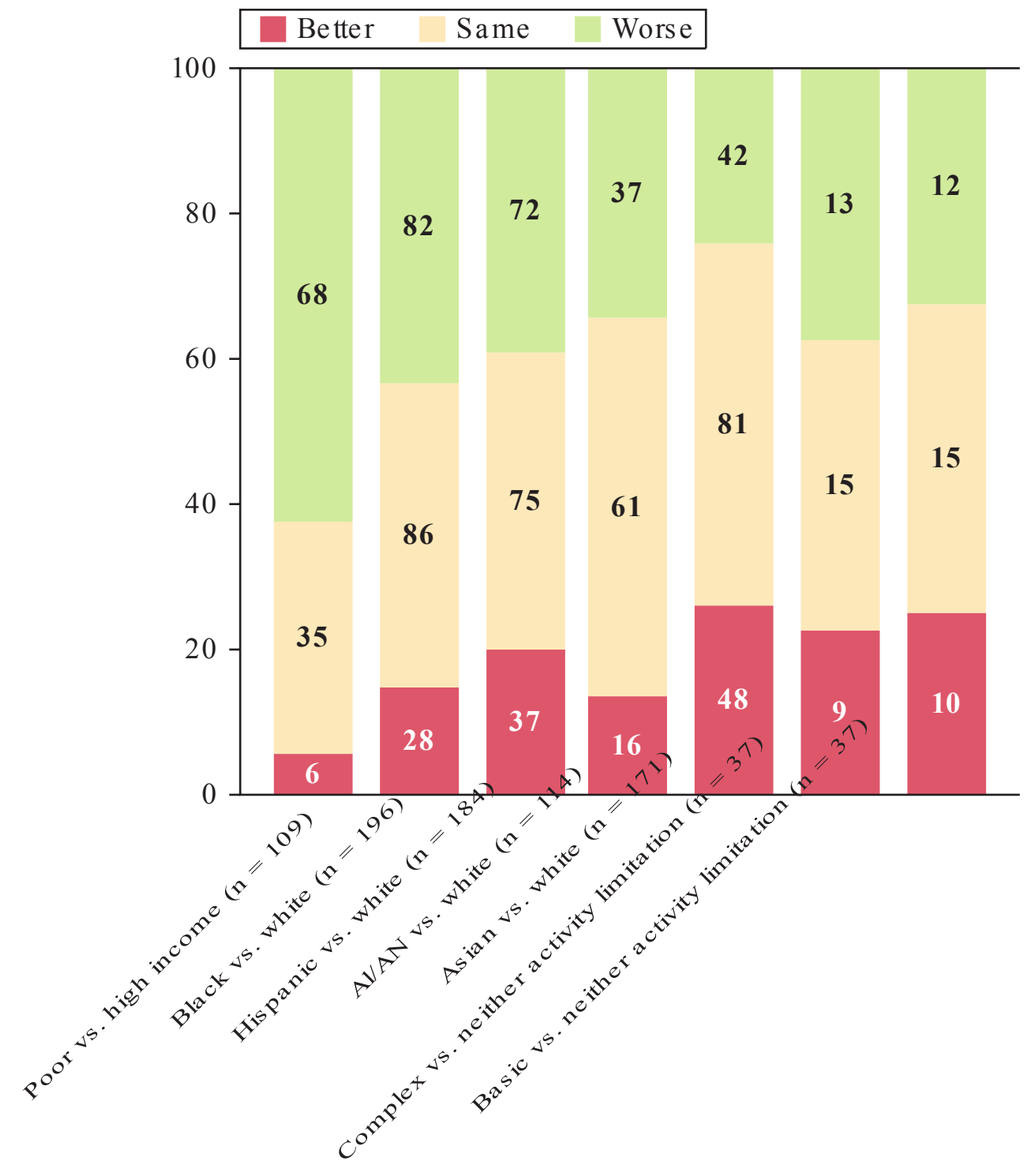


Figure 2-2. In 2010–2011, analysis performed by the Agency for Health Research and Quality as a part of the National Healthcare Disparities Report (2013) found that African Americans (blacks) and Hispanics received worse care than whites for about 40% of quality measures. American Indian/Alaskan Natives (AI/AN) received worse care than whites for one-third of quality measures. Asians received worse care than whites for about one-quarter of quality measures but better care than whites for about 30% of quality measures. Poor people received worse care than high-income people for about 60% of quality measures. People with basic or complex activity limitations received worse care than people with neither type of activity limitation for about one-third of quality measures and better care for about one-quarter of quality measures. (Based on Figure H.7 Available at: http://www.ahrq.gov/sites/default/files/publications/files/2013highlights.pdf.)
Key: AI/AN = American Indian/Alaska Native; n = number of measures.
Better = Population received better quality of care than reference group.
Same = Population and reference group received about the same quality of care.
Worse = Population received worse quality of care than reference group.
Note: For each measure, the most recent data available to our team were analyzed; for the majority of measures, this represents data from 2010 to 2011. Basic activity limitations include problems with mobility, self-care, domestic life, or activities that depend on sensory functioning. Complex activity limitations include limitations experienced in work or in community, social, and civic life.

higher rates of preventable hospitalizations for ambulatory care–sensitive conditions and worse blood pressure, diabetes, and lipid control than white beneficiaries.[25,26] Thus, the evidence suggests that patients like Mr. Mason and Mr. Dixon often receive unequal care even when they have the same type of health insurance.

SOCIOECONOMIC STATUS

Although less research in the United States has examined health-care disparities associated with an individual's socioeconomic status, the limited findings are consistent with the notion that those with less social status experience worse quality of care. Findings from the National Healthcare Disparities Report indicate that individuals who are poor or who live in less affluent communities receive fewer preventive care services such as mammograms and dental visits, have higher rates of avoidable hospitalizations, and are more likely to receive inappropriate medications when they see a physician for care.[23] These socioeconomic disparities do not seem to be exclusively due to inequities in insurance coverage. For example, even in the United Kingdom where there is universal coverage and health care is free at the point of care, primary care practices serving lower-income populations have historically had lower quality of preventive care.[27,28]

NEED AND PREDISPOSING FACTORS

If differences in health care according to race/ethnicity and socioeconomic status are not entirely attributable to differences in a dominant "enabling" factor such as health insurance, could non–health-care system factors explain these differences? For example, perhaps there are differences in health-care needs, such as disease severity, or predisposing factors, such as patient beliefs and preferences, that might account for the differences found in the National Healthcare Disparities Report. Rather than representing health-care inequity, might these observed differences in the use of health care simply represent a health-care system responding reasonably to patients with differing needs and interests?

Many of the findings on health-care differences that appear in the National Healthcare Disparities Report and similar analyses are based on data obtained from patient surveys and administrative records (e.g., billing records) that lack clinical detail about patients' clinical needs and preferences for care. Some studies have found that the magnitude of the differences in patterns of care is diminished after more thoroughly accounting for differences in the need and preferences for care across patient groups. However, in most cases, the differences in care patterns persist. For example, studies in emergency departments have demonstrated that African Americans and Latinos are less likely than whites to receive opiates for pain management of broken limbs.[29-32] Although these studies did not specifically investigate patient preferences, the findings suggest that physicians' assessments of patients' need for care are influenced by not only physiologic information but may also be influenced, consciously or subconsciously, by race or ethnicity. Some studies of patients with acute coronary syndromes, similar to the coronary events experienced by Mr. Mason and Mr. Dixon, have examined detailed information on coronary anatomy and failed to find clinical differences in underlying disease status that would explain the difference in rates of revascularization for African-American and white patients.[33-35]

Other studies have compared rates of refusal of recommended major procedures between white and minority patients and found relatively small differences in refusal rates that do not explain the observed differences in the use of these health-care services across racial and ethnic groups.[34,36] Thus, research suggests that differences in rates of patient refusal of invasive procedures rarely explain why patients like Mr. Dixon tend to be less likely than patients like Mr. Mason to undergo coronary revascularization.

A final consideration is whether some disparities represent inappropriately excessive care for privileged patients rather than inappropriately low use among vulnerable populations. Several studies have investigated this question for patients with coronary heart disease. Investigators demonstrated that white patients were more likely than African-American patients with the same severity of illness to receive coronary artery bypass surgery.[37] Comparison of the results of white and African-American Medicare patients who received coronary artery bypass surgery against well-established clinical criteria has revealed that some white patients were more likely than African-American patients to be inappropriately "overtreated" using surgery.[38] However, the degree of undertreatment among African-American patients was substantially greater than the amount of overtreatment among white patients. Furthermore, one study has shown that African-American patients with cardiovascular disease had a higher mortality than white patients because the African-American patients received lower use of appropriate surgical treatments.[35] Even for low-cost cardiovascular treatments such as prescribing of aspirin, African Americans are less likely to receive appropriate therapy than white patients for all levels of coronary heart disease risk.[39]

After conducting an extensive literature review of studies comparing the use of health-care services across racial and ethnic groups, and across a wide spectrum of clinical conditions, the authors of the Institute of Medicine's Unequal Treatment report concluded that they

were "struck by the consistency of the research findings: even among better controlled studies, the vast majority indicated that minorities are less likely than whites to receive needed services, including clinically necessary procedures."[40,41] The report also concluded that most of the differences in care could not be explained by differences in patient preferences or the need for care. They concluded that discrimination and health system characteristics (e.g., lack of interpreters or fragmentation in care) are the main basis for the differences in care that minorities receive.

BIAS, STEREOTYPING, AND DISCRIMINATION

It is difficult for research to measure directly and objectively the attitudes and motivations underlying the behavior of clinicians. Thus, determining whether health-care disparities can be attributed to bias, stereotyping, or discrimination tends to be a "diagnosis of exclusion." The Institute of Medicine's Unequal Treatment report raises serious concerns that health-care disparities may result from bias, stereotyping, and potentially racism among people working in the health-care system, especially given that the lower-quality health care received by racial and ethnic disparities cannot be explained by differences in the need for care, or patient preferences. This sort of bias and stereotyping may be subconscious. These issues are not confined to the United States. For example, there is a report of bias and stereotyping related to patients' ethnicity among health professionals in the United Kingdom.[42] While less studied, it seems likely in the context of other well-documented social inequities that this sort of bias, stereotyping, and even discrimination also occurs among health professionals in the United States and elsewhere based on other patient characteristics such as gender and social class.

ADDRESSING HEALTH-CARE DISPARITIES

The Institute of Medicine has proposed a broad set of recommendations at the policy, health system, provider, and patient levels that can contribute to eliminating health-care disparities (see "Core Competency").[40] These recommendations include strategies such as increasing the diversity of the health-care workforce, structuring payment systems so that they support equitable distribution of health-care resources, and increasing patient education programs that can empower patients, particularly those from vulnerable groups, to take a greater role in their own medical decision making. This book explores many of the actions that can be taken by health policy decision makers, health professionals, educators, and researchers to eliminate disparities in health care. It is clear that improvement has and can be accomplished. This section summarizes some of the key approaches that health professionals can adopt to reduce health-care disparities.

RECOGNIZE HEALTH-CARE DISPARITIES AS A PROBLEM

Although many health-care professional organizations have endorsed a position that all patients, regardless of race, ethnic origin, nationality, primary language, or religion, deserve high-quality health care,[43] considerable evidence documents that many inequities exist and persist over time in actual practice. One recent study found that physicians, medical students, and members of the public have very different views about health-care disparities, with physicians being the least likely to agree that there is unfairness in the health-care system based on a patient's race or class.[44] Thus, one of the first steps in eliminating health-care disparities is to inform health professionals of the problem so that effective interventions can be established to reduce the inequities. Although progress is slow and uneven, health professionals have demonstrated that they are capable of making adjustments to decrease disparities. For example, the provision of an interpreter for patients with limited English proficiency was once seen as an exception, but it is increasingly common and recognized as a necessary accommodation for patients who require this assistance.[45]

UNIVERSAL HEALTH INSURANCE

After numerous attempts spanning more than a century, the United States through the passage in 2010 of the ACA took a significant step toward universal health insurance coverage.[46] The ACA is expected to cover more than 26 million of the estimated 55 million uninsured Americans through either Medicaid or subsidized private insurance, depending on an individual's income level.[47] Extensive research documenting the critical importance of health insurance for gaining access to high-quality care contributed to the passage of the law. The Institute of Medicine estimated that a lack of health insurance accounts for 18,000 deaths annually in the United States.[18] As noted earlier, minorities and low-income individuals are particularly likely to be uninsured, and therefore stand to gain the most from this law.

Despite its efforts to expand insurance coverage, the ACA falls short of the fully universal coverage that exists in most developed nations. Individuals in the United States who are undocumented immigrants are not eligible for Medicaid or subsidized private insurance coverage under the ACA; most of these individuals and families will therefore remain uninsured and continue to delay seeking care and have unmet health-care needs.

Challenges to implementing the ACA also impede its improving access to care and reducing health-care disparities. The Supreme Court, in response to challenges to the law's legitimacy under the Constitution, upheld most of the key components of the ACA but made the expansion of coverage through state-administered Medicaid programs optional for states to implement, rather than mandatory as called for by the ACA. As of September 2015, 30 states and the District of Columbia had elected to expand Medicaid coverage under the ACA. Since full implementation of the ACA, about 18 million uninsured people have gained coverage. However, many low-income Americans living in states that have not elected to expand Medicaid coverage-mainly states in the southern region of the United States with large concentrations of economically disadvantaged, uninsured populations-continue to not benefit from expanded Medicaid coverage. Were all of the states to expand Medicaid coverage, an additional 5 to 6 million uninsured individuals would gain coverage.[48]

States also face a challenge in educating those who are uninsured about the necessary steps to enroll in health insurance programs. Despite the fact that coverage will either be free or highly subsidized by the federal government, many uninsured individuals may perceive it to be too costly to sign up for coverage. Language and other communication barriers may complicate the ability to educate uninsured individuals about the potential benefits of seeking coverage and the methods for doing so. Some uninsured may falsely believe that they will place their legal immigration status at risk by seeking health insurance coverage (see Chapter 29).

Participating in advocacy efforts to help patients take advantage of new coverage opportunities afforded by the implementation of the ACA is one way to address disparities. Health professionals can help educate patients about the widened array of public and private insurance programs in the United States, in order to more effectively assist individual patients to navigate the health-care financing bureaucracy and successfully obtain the coverage they may be entitled to receive (see Chapter 4).

ACCESS AND DELIVERY OF HEALTH SERVICES

Universal health insurance is a critical step on the way to achieve health-care equity, but as the experience of other countries shows, on its own it is unlikely to be enough. Even when insured, vulnerable populations still face deficiencies in the enabling resources that would permit them to obtain equitable health outcomes. Some of these deficiencies may be related to inequalities in the distribution and availability of facilities and technology, such as the preferential location of specialty hospital units in higher-income urban neighborhoods rather than in inner-city and rural communities.

The quality of health-care providers available to different groups of patients may vary as well. One analysis of racial differences in Medicare patients' outcomes after coronary artery bypass graft surgery found that the increased mortality among African-American patients compared with whites disappeared after controlling for the quality of the hospital care where patients were obtaining their procedures.[49] Health-care organizations should reach out to surrounding community members and involve community representatives in planning and quality improvement initiatives.[43]

The organization of the health-care delivery system may also play a role in reducing health-care disparities. While it is unclear whether it is due to the financing or the organization of providers in these arrangements, there have been some reports of improvement in health-care disparities in Medicare- and Medicaid-managed care.[50,51]

PROVIDERS IN UNDERSERVED AREAS

One of the most important of the non–insurance-related enabling resources is the human resources of the health-care system: the physicians, nurses, pharmacists, dentists, physician assistants, and many other essential health-care workers. Health-care disparities related to human resource enabling factors may result from geographic maldistribution, at least in part. Research has shown that communities in California with a relatively high proportion of minority residents have a much lower supply of physicians, dentists, nurse practitioners, and physician assistants than neighborhoods that have fewer minority residents.[15,52,53] This research also has shown that African-American and Latino health professionals are much more likely than their white counterparts to work in underserved communities with fewer health-care resources. Similarly, health professionals who grew up in rural communities are more likely to ultimately practice in rural communities than those who grew up in urban areas.

Those who gain coverage as a part of the ACA will increase the demand for health-care services to address unmet needs due to a previous lack of coverage. This increased demand among the newly insured will stress the capacity of the health-care system particularly in areas that had high rates of uninsured individuals and an inadequate number of available physicians. One strategy for addressing health-care disparities related to maldistribution of human resources is to recruit more underrepresented minorities and students from rural backgrounds into the health professions.

Adequate payment rates are also an important strategy for increasing the number of practitioners in underserved areas. Medicaid is the dominant payer in most underserved communities; in most states, Medicaid payment rates to physicians and other practitioners are substantially lower than from the fees paid by other insurers.[54] Low payment rates in Medicaid discourage physicians from participating in the care of low-income patients.[55] The ACA included a Medicaid payment increase for primary care practitioners to encourage physicians to participate in the Medicaid program, but there are concerns that this policy's impact may be muted because the payment increases were only in effect during 2013 and 2014.

Other countries go even further to support primary care practitioners' ability to care for the poor. For example, in the United Kingdom, the National Health Service has encouraged physicians to work in less affluent areas by paying higher capitation rates to general practitioners in those communities and by preventing new practices opening in more affluent areas with adequate supply of physicians. Although these policies have produced a nearly equal distribution of general practitioners per 1000 population across neighborhoods, this distribution is still considered by some to be inequitable given the much higher burden of illness and health-care needs in disadvantaged communities. From the perspective of need, the least affluent therefore can remain underserved even in a universal coverage system (although the degree is typically less extreme than in systems without universal coverage).[56,57]

CLEAR COMMUNICATION AND CULTURALLY COMPETENT CARE

Providers' assessments of patients' need for care have a subjective component and patients' preferences for care are somewhat dependent on the information patients receive from providers. Thus, one strategy is to improve health professionals' cultural competence so that they can more effectively evaluate and communicate with diverse patient populations. Increasing the racial, ethnic, and socioeconomic diversity of health professionals and incorporating within health professions training programs curricula on the interpersonal and communications skills necessary for effectively caring for vulnerable populations might accomplish this.

GUIDELINES OR STANDARDS IN THE PROCESS OF CARE

Implementation of evidence-based clinical guidelines that establish an explicit standard of care that is applied to all patients with the same clinical status or health-care need appears to be a way to reduce disparities. A study of patients with end-stage renal disease found that disparities by race in the adequacy of dialysis treatment diminished after the adoption of an evidence-based treatment guideline.[58] This study suggests that guidelines, along with monitoring and feedback of clinical performance benchmarked to an evidence-based guideline, may reduce the degree of subjective judgment and potential bias in clinicians' clinical decision making, thereby helping to mitigate health-care disparities. A related and promising approach is for health-care delivery organizations and payers of care to define explicit guidelines or standards in the process of care for certain conditions, and to monitor processes of care for different patient populations with these conditions based on race/ethnicity, socioeconomic status, or other characteristics to ensure that all groups achieve an equivalently high standard of quality.

PAYMENT INCENTIVES

Payment incentives tied to health-care quality can increase accountability in health care. While the focus of these activities is typically on health-care quality for a population as a whole, there is some research from the United Kingdom, where this approach has been widely adopted in primary care, that pay for performance can contribute to reducing health-care disparities as well. The United Kingdom implemented a program in 2004 to reward primary care practices based on their quality measured by 48 clinical indicators. The average quality improved in practices over time. While measured quality was initially lower in practices serving less affluent patients, differences were almost eliminated by year 3.[59] This indicates that disparities are amenable to intervention, but they require sufficient time to be effective. Eliminating ethnic disparities has proven to be more challenging and they have not narrowed down as rapidly over time as socioeconomic disparities in the United Kingdom's primary care pay-for-performance program.[60]

CONCLUSION

The evidence for the existence of health-care disparities is overwhelming. Disparities exist in access to care and in the quality of care that is delivered once patients access the health-care system. Recognizing health-care disparities as a problem is an important first step, but recognition alone will not bring about positive change. The passage of the ACA provides a major opportunity in the United States to decrease health-care disparities related to financial barriers to care; however, the experience in the United States and internationally suggests that health-care coverage alone will not be sufficient to fully achieve health-care equity.

- Health-care disparities reflect systematic differences in access to or quality of care between more and less privileged groups that cannot be explained by the differences in the need for care or preference for care among the individuals in these groups.
- Minorities and low-income individuals suffer health-care disparities in part because they have less access to high-quality care.
- Even among those patients who have accessed care and whose needs have become visible to the health-care system, there are systematic differences in the receipt of services by groups of patients who vary by characteristics of social privilege.
- Provider bias, stereotyping, and perhaps even racism may contribute to health-care disparities.
- Recognizing health-care disparities as a problem is an important first step, but providers need to participate in a broad range of changes at the policy, system, and provider level in order to eliminate them.

Institute of Medicine Recommendations for Addressing Health-Care Disparities General Recommendations

- Increase awareness of racial and ethnic disparities in health care among the general public and key stakeholders.
- Increase health-care providers' awareness of disparities.

Legal, Regulatory, and Policy Interventions

- Avoid fragmentation of health plans along socioeconomic lines.
- Strengthen the stability of patient–provider relationships in publicly funded health plans.
- Increase the proportion of underrepresented US racial and ethnic minorities among health professionals.
- Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.
- Provide greater resources to the US Department of Health and Human Services Office for Civil Rights to enforce civil rights laws.

Health Systems Interventions

- Promote the consistency and equity of care by evidence-based guidelines.
- Structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities.
- Enhance patient–provider communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.
- Support the use of interpretation services where community needs exist.
- Support the use of community health workers.
- Use multidisciplinary treatment and preventive care teams.

Patient Education and Empowerment

- Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.

Cross-Cultural Education in the Health Professions

- Integrate cross-cultural education into the training of all current and future health professionals.

Data Collection and Monitoring

- Collect and report data on health-care access and use by patients' race, ethnicity, socioeconomic status, and (where possible) primary language.
- Include measures of racial and ethnic disparities in performance measurement.
- Monitor progress toward the elimination of health-care disparities.
- Report racial and ethnic data by Office of Management and Budget categories, and use subpopulation groups where possible.

Research Needs

- Conduct further research to identify sources of racial and ethnic disparities and assess intervention strategies.
- Conduct research on ethical issues and other barriers to eliminating disparities.

Source: Institute of Medicine. Insuring America's Health. Washington, DC: National Academies Press, 2004.

DISCUSSION QUESTIONS

1. African-American women get breast cancer at the same rate as white women, yet African-American women are more likely to die from this disease. Does this represent a health-care disparity? How would you determine if the problem results from access barriers or the quality of care women receive once they have been diagnosed with cancer?
2. Should you include information on a patient's race in the history and physical examination? Should you include other information on the patient's social class such as education, occupation, or income? In what ways do you think it is helpful or harmful for patient care to include this information?
3. Are there health-care disparities where you practice medicine? How well does your practice setting meet the health-care needs of everyone in your community? Which groups of patients are excluded? Within the practice, do you think some patients receive

suboptimal care? How might you assess your practice to determine if there are health-care disparities? What policy, system, and provider level changes do you think would be most useful for eliminating health-care disparities in your practice setting?

RESOURCES

http://health-equity.pitt.edu/index.html. Minority Health and Health Equity Archive

http://www.ahrq.gov. Agency for Health Research and Quality.

http://www.amsa.org/hp/uhcres.cfm. American Medical Students Association.

http://nursingworld.org/readroom/rwjpaper.htm. American Nurses Association.

http://www.kff.org. Kaiser Family Foundation Commission on Medicaid and the Uninsured.

http://www.pnhp.org. Physicians for a National Health Program.

http://www.census.gov/hhes/www/hlthins/hlthins.html. U.S. Census Bureau.

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Chapter 3

Financing and Organization of Health Care for Vulnerable Populations

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Objectives

- Describe the core functions of health-care financing.
- Explain how health-care financing may be tailored to address the challenges that vulnerable populations face.
- Describe the provisions in the Affordable Care Act and how they affect the financing and organization of health care.
- Describe the types of providers that constitute the safety net.
- Explain why the organization and financing of the health-care safety net does not adequately meet all the health needs of vulnerable populations.
- Articulate the arguments for increasing the numbers of primary care safety net providers to improve the access for vulnerable populations.

INTRODUCTION

> John Walsh is a 56-year-old man with essential hypertension and type 2 diabetes. Since being laid off from full-time work, Mr. Walsh and his dependents, a wife and two children, were left without insurance. Neither of his part-time jobs, as a security guard and a deliveryman, offered any health insurance benefits.

Mr. Walsh and his family members have slipped through the cracks of a fragmented system of health-care insurance coverage. The United States has lagged behind almost all developed nations in establishing universal health-care coverage. In 2013, there were approximately 40 million uninsured people in the United States.[1] The majority of the uninsured live in households with at least one full-time working adult.[2] Absence of insurance creates obstacles to obtaining health care in a timely way. Without a means to pay, patients forgo necessary health services resulting in worsening health.

In 2010, President Obama signed into law the Affordable Care Act (ACA). The ACA establishes an individual mandate for health insurance coverage and has numerous provisions to assist low-income individuals with financing to obtain health insurance. Nonetheless, the ACA has not removed all barriers to health care, nor has it resulted in universal coverage for Americans. The high costs of care and the dearth of providers serving vulnerable populations are persistent and substantial challenges.

A safety net system exists to care for those who face barriers in access to care, such as Mr. Walsh. The safety net is a geographically variable patchwork of providers available to care for individuals with barriers to care, such as a lack of insurance or those residing in a community that is medically underserved because of an inadequate supply of practitioners. Individuals with low family income, minority status, rural residence, limited English proficiency, and

poor health status are more vulnerable to not receiving needed health care, and when they do obtain care, they are more likely to receive it from safety net providers. Even in nations with universal financial coverage, safety net programs often exist to address the needs of populations with special access challenges, such as the homeless, recent immigrants, and residents of remote rural regions.

The financing and organization of the health system are the starting points for understanding how health care is delivered to populations. No health system has enough resources to meet the demands of every patient served, not even the United States, which spends close to 18% of its gross domestic product on health. The ways in which health care is financed and organized represent choices about who will receive what services under which conditions.[3]

This chapter describes the financing of health care in the United States, changes in the financing of health insurance coverage related to the ACA, and the architecture of the safety net available to care for vulnerable populations.

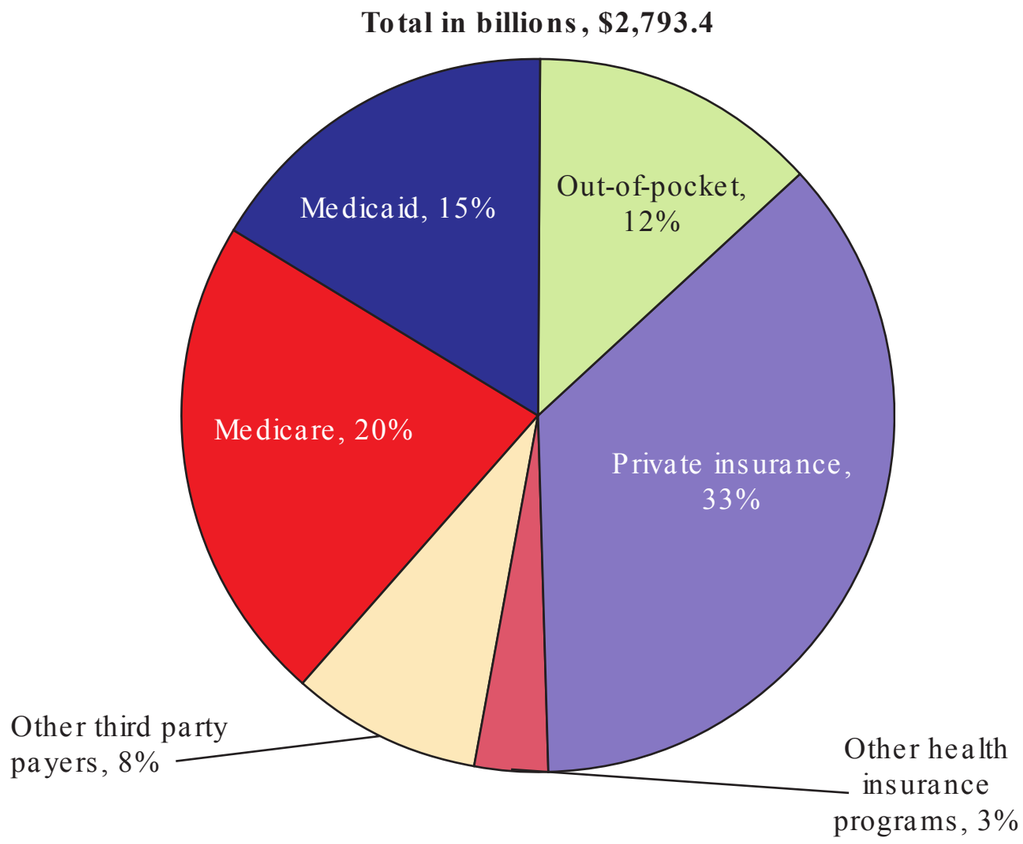


Figure 3-1. National health-care source of funds, 2012. (Source: Centers for Medicare and Medicaid Services, 2012 National Health Expenditure Data [Online]. Available at http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/tables.pdf.)

HEALTH SYSTEM FINANCING

Financing of health systems can be characterized by the sources of health system funds and by how the collected funds are structured, whether by pooling to spread risk and ensure financial security of individuals and families or requiring patients who lack insurance coverage to pay directly in order to receive services.

REVENUE COLLECTION

Revenue collection refers to where the money to pay for health care comes from (i.e., the funding sources) and how these resources are obtained (i.e., contribution mechanisms). Nearly all health system revenue in developed nations comes from individuals—as workers, as tax payers, and as patients. In the United States, public funds are raised as taxes on workers, such as the Medicare wage tax, or from federal and state income taxes, and a limited amount from corporate and other types of taxes. Private sector funds come from insurance premium contributions that employees and their employers make. Employers consider their portion of the premium payment to be part of their employee's total compensation package; so, in fact, it is the employee who actually pays both their own and their employer's contributions.

Out-of-pocket payments that insured patients incur when they use health services are the second source of private sector funding. An out-of-pocket payment may be made in the form of deductibles (a fixed amount of money that a patient is responsible for paying before the insurer also pays), coinsurance (a percentage of health-care costs that a patient pays up to a maximum out-of-pocket limit), and copayments (a fee paid at the time of every visit). These three types of payments are forms of cost sharing, and are used by insurers to reduce utilization and shift costs to individuals using services. For low-income families, cost sharing can be so burdensome that they forgo necessary care with inimical effects on their health.[4]

A second type of out-of-pocket payment results from direct payments made to providers by patients with no insurance. Direct payments offer no financial protection and can be very burdensome for vulnerable populations.

The distribution of the various sources of health system revenue in the United States is shown in Figure 3-1. Note that health system revenue in the United States is collected in approximately equal proportions using public and private sector mechanisms. This pluralistic mix of revenue contributions to the health system is one of the many obstacles in the United States to achieving a system of universal coverage.

RISK POOLING

When revenue is collected on a prepaid basis (rather than at the time care is received), and aggregated across many individuals, an insurance risk pool is formed. Protecting individuals from the financial impact of health-care costs is best achieved with prepayment and risk pooling. At the individual level, health-care events are largely unpredictable and, when they occur, can be costly. By pooling resources, health insurers, whether they are private plans or government-sponsored insurers, spread the risk of

financial loss due to health care across the all contributors. This provides a level of financial security to a given individual that cannot be achieved without risk pooling. To sustain themselves, risk pools require large numbers of healthy individuals who in effect cover the costs of those who are sick and require more resources. Individuals are willing to participate in risk pools because of the uncertainty of illness at the individual level.

Low-income individuals may not have the financial means to participate in a health insurance risk pool. Individuals with no health insurance coverage must pay for services entirely out of pocket, rendering low-income individuals in general and those with high health-care needs in particular susceptible to financial hardship, because they are not part of a financing pool that shares financial risk.

UNDERINSURANCE

Even when insured, many individuals may have plans with high amounts of cost sharing that cause financial hardship. Having insurance with high levels of cost sharing is a form of underinsurance, which can pose as large a financial barrier to care as having no insurance at all. Underinsurance refers to insurance that does not provide adequate financial coverage to address an individual or family's health needs. High-deductible health plans are an example of insurance that provides coverage for expensive care, but requires patients to cover the first several thousand dollars of health-care costs on an annual basis. One-third of low-income insured individuals are actually underinsured.[5] When enrolled in high-deductible health plans, low-income families and individuals with chronic conditions are at increased risk for delaying or forgoing needed health care, including physician visits and medications.[6]

The ill effects of being uninsured extend beyond delaying care: poor health that results from lack of insurance reduces income by an estimated 15–30%, and people with lower incomes are less likely to have health insurance.[7,8] Costs associated with illness and injury in the United States are the most common reason to declare personal bankruptcy,[9] and many of these bankruptcies have been among insured patients with insufficiently comprehensive benefits.

Health Insurance

Most industrialized and many developing nations provide health-care coverage to their populations as a form of social security. In the United Kingdom, the National Health Service is funded by general taxes, whereas in Germany, sickness funds are sponsored by worker payroll taxes and government contributions. The ACA, signed into law in 2010, is intended to move the United States closer to universal coverage through a combination of private insurance regulatory changes and increased availability and affordability of insurance for low-income persons.

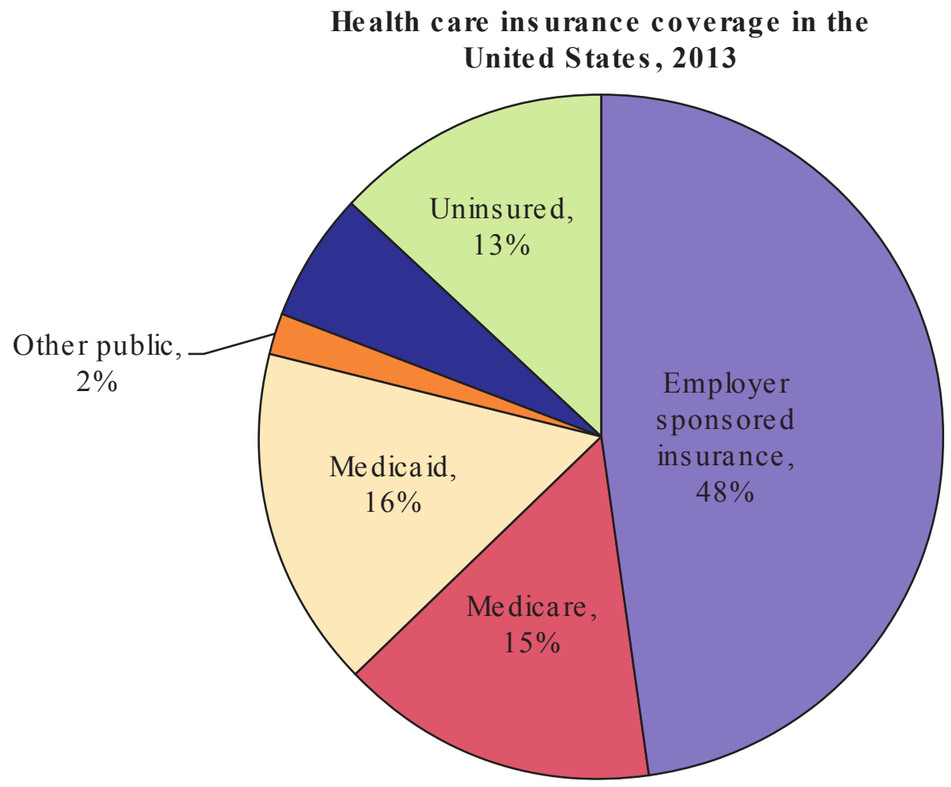


Figure 3-2. Health-care insurance coverage in the United States, 2013. Categories are mutually exclusive; persons cannot be in more than one insurance category. The "Other Public" insurance category includes nonelderly Medicaid enrollees as well as individuals covered through the military or Veterans Administration. (Source: Kaiser Family Foundation, 2014 estimates. Available at http://kff.org/other/state-indicator/total-population/.)

The major provisions to expand health insurance coverage as a part of the ACA were implemented in 2014. In 2013, 13% of Americans reported that they were uninsured; 48% reported that they obtained coverage through a voluntary system of employer-sponsored health-care insurance benefits, 6% purchased individual private insurance policies, and most of the remainder were covered by two major public insurance programs, Medicare and Medicaid (Figure 3-2). For low-income persons younger than 65 years, just 10% received employer-sponsored health insurance, 8% purchased it as individuals, and 27% were uninsured (the balance got their coverage from publicly sponsored programs).[10,11]

Publicly Sponsored Health Insurance

Health-care policy in the United States focused on improving insurance coverage rates and has largely developed via an "incrementalist" approach in which government confers health benefits to defined categories of the population.[12] Medicare, the Indian Health Service, and the Veterans Administration's (VA) medical system are programs sponsored by the federal government, and are entitlements where, respectively, all US citizens aged 65 years and older, Native American/Alaskan natives, and veterans are guaranteed insurance coverage. These three programs contrast with Medicaid, which is a means-tested publicly sponsored insurance benefit that, prior to

implementation of the ACA, limited eligibility to a subset of poor individuals. Because of their size and importance to vulnerable populations, we discuss Medicare, Medicaid, and Children's Health Insurance Program (CHIP) in more detail in the following.

Medicare

Medicare is a federal program insuring the elderly, disabled, and those with end-stage renal disease.[13] The program was created in 1965. All elderly US citizens aged 65 years and older who have paid into Social Security for at least 10 years are guaranteed coverage under Part A ("hospital insurance"). Inpatient services, short-term stays at skilled nursing facilities, hospice care, and some home health care are paid through this program, funded through a payroll tax on currently employed workers.

Medicare Part B ("medical insurance") provides limited coverage of outpatient services and requires beneficiaries to pay a monthly premium. Many elderly individuals without sufficient incomes to pay for Part B premiums are eligible to have state Medicaid programs pay their Part B premiums, as well as some of their other out-of-pocket costs. Individuals who receive both Medicare and Medicaid coverage are termed "dual-eligibles."

The 1997 Balanced Budget Act instituted Medicare Part C, called Medicare + Choice, to allow beneficiaries to opt into managed care plans in lieu of enrolling in Medicare Part A and Part B. In 2014, 30% of Medicare beneficiaries were enrolled in a Medicare Advantage plan.[14]

The Medicare Prescription Drug, Improvement and Modernization Act of 2003 added Medicare Part D, a voluntary prescription drug benefit.[15]

Medicaid

Medicaid was also created in 1965, but unlike Medicare, which is funded from federal and beneficiary funds, Medicaid is funded by federal and state revenues with no beneficiary premiums. The amount of federal matching funds a state receives reflects the economic status of a state as well as the size and eligibility profile of a state's vulnerable populations. Federal guidelines govern the administration of the programs but allow for substantial flexibility in coverage and implementation, rendering each state's Medicaid program unique.

Medicaid beneficiaries must meet the residency standards of the state and federal immigration standards, and prior to the ACA, be a member of a population eligible for coverage (e.g., pregnant women, children, and disabled persons), and satisfy income and asset requirements. As a result of these "categorical" eligibility criteria, the main classes of Medicaid beneficiaries are low-income children and their parents, pregnant women, low-income disabled individuals (who must first meet state requirements for Supplemental Security Income, SSI), and low-income elderly with Medicare coverage.

The ACA attempted to standardize Medicaid eligibility by requiring all states to expand eligibility to people with incomes up to 133% of the federal poverty level and eliminating categorical eligibility criteria; this expansion is 100% funded by the federal government for 2014–2016, decreasing to 90% federal contribution by 2020 and beyond. The Supreme Court later ruled that requiring states to change their Medicaid eligibility rules was unconstitutional, and that these policy reforms must be voluntary for states instead of mandatory. By the end of 2015, 30 states and the District of Columbia have opted to participate in the ACA's expanded Medicaid program.

Children's Health Insurance Program

The Children's Health Insurance Program (CHIP) was created in 1997. Under this legislation, states were offered new funds to expand Medicaid or set up new programs to cover children above Medicaid income thresholds but below 200% of poverty level. Some states have chosen to extend this program beyond children to include the uninsured parents of eligible children. CHIP benefits are generally similar to those of Medicaid. Over the past decade, expansions in Medicaid eligibility and enactment of CHIP have reduced rates of uninsurance for children. The ACA requires states to maintain current income eligibility levels for children in CHIP until 2019.

AFFORDABLE CARE ACT

The Affordable Care Act (ACA) is the most significant change to the US health-care delivery system since the creation of Medicare and Medicaid in 1965. Table 3-1 provides a summary of the key provisions of the ACA related to health care for vulnerable populations.

One of the most important elements of the ACA is the prohibition to exclude individuals with preexisting conditions from purchasing health coverage. Before the ACA, insurers could charge individuals with preexisting health conditions, such as heart disease, diabetes, and arthritis, much higher premiums, decide not to cover costs related to the treatment of a specific condition, or deny coverage completely. The ACA requires health plans to guarantee issue—that is, cover all applicants with a minimum standard benefit package and offer the same rates regardless of preexisting conditions or gender.

For guaranteed issue to be workable, everyone needs to be covered, both healthy and sick, so the risk can be spread across a larger pool of enrollees. This is the reason why the ACA also created an individual mandate, which, beginning in 2014, requires individuals to obtain insurance, either through their employer, in the Marketplace (health insurance exchange), or via a public program. Those individuals not obtaining coverage face a financial penalty for lack of compliance.

Table 3-1. Summary of ACA Implications for Vulnerable Populations

I. Improvement and Expansion of Health Insurance Coverage

Overall improvements to health insurance coverage

Guaranteed issue

- Prohibit the exclusion of individuals with preexisting conditions

Individual mandate

- Requires most US citizens to have health insurance

Coverage of prevention

- Eliminate cost sharing for preventive services recommended by the US Preventive Services Task Force

Changes to private insurance

- Provide coverage for dependent children up to age 26
- Prohibit lifetime and annual limits on dollar value of coverage
- Medical loss ratio: Require health plans to report the proportion of premium dollars spent on clinical series vs. administrative costs and provide rebates to consumers if that amount is less than 85%

Employer-sponsored plans

- Require employers with more than 50 employees to provide health coverage for full-time employees
- Provide small employers (less than 50 employees and average annual wages less than $50,000) that purchase health insurance for employees with a tax credit

Individual/Small group market

- Create state-based exchanges (Marketplaces) through which individuals and small businesses (up to 100 employees) can purchase coverage
- Provide premium credits for eligible individuals and families with incomes between 133% and 400% FPL
- Provide cost-sharing subsidies for eligible individuals and families with incomes between 133% and 400% FPL

Changes to public-sponsored coverage

Medicaid

- Expand Medicaid to cover eligible individuals with incomes up to 133% of FPL. Supreme Court later ruled this optional for states
- Create Medicaid Health Home option for chronically ill
- Provide states with new option for home and community-based services
- Temporary increase Medicaid payments for primary care providers to 100% of Medicare rates.
- Establish the community first choice option to allow states to provide home and community-based attendant services to Medicaid enrollees with disabilities

CHIP

- Require states to maintain current income eligibility levels until 2019 and extend funding through 2015

Medicare

- Phase down the coinsurance rate for prescription drugs in Medicare Part D from 100% to 25% (AKA Doughnut hole)
- Provide time-limited 10% bonus payment to primary care physicians

II. Noninsurance elements to improve care for vulnerable populations

Workforce

- Expand National Health Service Corps
- Provide 10% bonus payment to primary care providers and general surgeons practicing in HPSAs

PCORI

- Support comparative effectiveness research by establishing nonprofit Patient-Centered Outcomes Research Institute

Duals office within CMS

- Improve care coordination for beneficiaries covered dually by both Medicare and Medicaid by creating the Federal Coordinated Health-Care Office.

Innovation center within CMS

- Authority and funding to test, evaluate, and expand new models of care delivery and payment reform that will reduce expenditures while maintaining or improving quality of care

The ACA provides financial assistance to help low-income individuals comply with the individual mandate. In addition to providing federal support to states to expand Medicaid eligibility to all non-elderly individuals below 133% of the federal poverty level, the ACA provides affordability credits on a sliding scale for individuals between 133% and 400% of the federal poverty level to purchase health insurance through a Marketplace.

It is estimated that more than 18 million Americans have gained coverage since implementation of the ACA.[16] Even without all states electing to expand Medicaid, the Congressional Budget Office anticipates that within a few years more than 25 million Americans who otherwise would have been uninsured will have gained coverage as a result of the ACA.[17] However, millions of individuals in the United States will remain uninsured, including nearly 4 million residents living in states who have chosen not to expand Medicaid,[18] individuals eligible for Medicaid or subsidized private coverage who do not enroll,[19] and undocumented residents who remain ineligible for Medicaid and for the affordability credits to purchase health insurance through a Marketplace.

In addition to its impact on expanding health insurance coverage, the ACA reduces the risk of underinsurance by prohibiting health plans from placing lifetime and annual

limits on the amount of coverage and by preventing insurers from rescinding coverage after a patient is diagnosed with an expensive medical condition.

ORGANIZATION OF THE HEALTH-CARE SAFETY NET

In order for health insurance coverage to translate into improvements in health, it must facilitate access to care. While financial barriers to care are reduced by the availability of coverage, there are other barriers that challenge vulnerable populations' ability to use health-care coverage to receive health-care services. One major barrier is the availability of providers willing to accept a patient's form of coverage. Many of the same geographical areas where there are likely to be some of the largest expansions of health insurance coverage related to the ACA are also areas that have traditionally been underserved by health professionals. While the expansion of coverage will potentially provide patients from vulnerable groups with new options for where they might seek care, many either by choice or due to limited alternatives will continue to depend on the safety net for their care. Safety net providers are experienced in caring for vulnerable population groups and often have resources not found in other settings to support the provision of culturally competent care.

SAFETY NET PROVIDERS: WHO ARE THEY?

The US health-care safety net is a complex mix of primary care and specialty services (e.g., renal dialysis and care for persons with HIV-AIDS), hospital-based clinics and programs, community health centers, and other health-care providers that deliver services to vulnerable patients.

The composition of providers in a safety net varies greatly between communities and depends on factors such as a state's Medicaid policies, the socioeconomic composition of a community, the competitiveness of the local health-care market, and the existence of other programs for the poor and uninsured or special needs populations.[21-23] A diverse groups of practitioners, physician organizations, and hospitals provide services to vulnerable populations and can range from pharmaceutical programs for indigent patients to private physicians serving Medicaid patients to community health centers, free clinics, and hospitals providing uncompensated care. In most communities, the health-care safety net is not a formalized network of coordinated services.

CORE SAFETY NET PROVIDERS AND THEIR FUNDING

The Institute of Medicine report coined the phrase "core safety net providers" to refer to practitioners and health-care organizations that care for a substantial share of uninsured, Medicaid beneficiaries, and other vulnerable populations among the patients they serve.[22] Also called "providers of last resort," core safety net providers have organizational missions that mandate serving vulnerable populations within their communities or they are legally required to serve patients regardless of ability to pay. As a result, these providers tend to bear a disproportionate share of the burden in caring for those who are uninsured or covered by public insurance.[22]

Several government programs provide financial support for care to safety net providers as a supplement to what is reimbursed for the hospital care of specific patients covered by those programs. In 2013, providers' uncompensated care costs totaled $80 billion, with two-thirds ($53 billion) offset by government payments (Figure 3-3). The most significant of these special streams of payments is Disproportionate Share Hospital (DSH) Payments, provided separately by Medicaid and Medicare. Hospitals receive Medicaid DSH funds when they exceed a designated threshold of hospital bed days for Medicaid and uninsured patients and Medicare DSH funds when they exceed a designated threshold for low-income Medicare beneficiaries dually covered by Medicaid. Medicare also contributes supplemental funds to safety net teaching

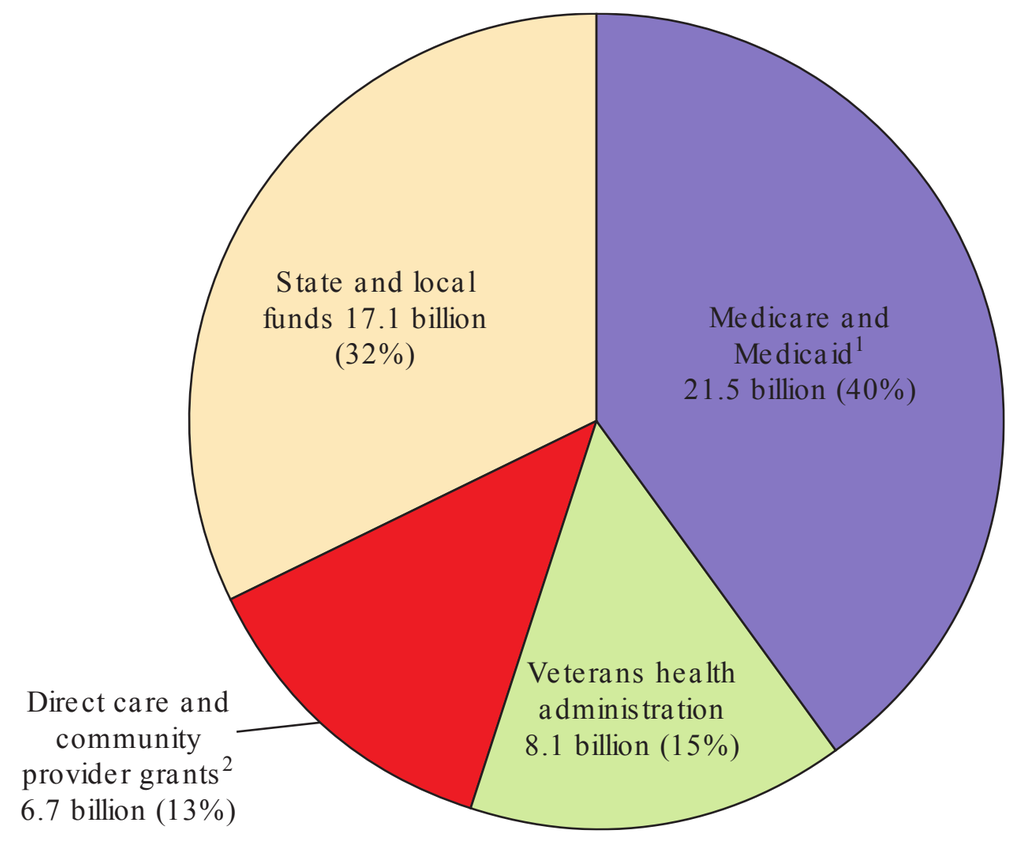


Figure 3-3. Distribution of government expenditure on $53.3 billion in caring for the unreimbursed, 2013.

[1]Payments made primarily through Medicaid DSH (both Medicaid and Medicare), upper payment limit (Medicaid), and IME (Medicare) mechanisms. Medicare and Medicaid DSH (disproportionate hospital share payments) are payments made to hospitals serving a disproportionately large share of the low-income and uninsured patients. Medicare IME payments are made to teaching hospitals and their residency programs in recognition for the role of teaching hospitals as core safety net providers.

[2]Federal monies at the Indian Health Service, Community Health Centers, Ryan White CARE Act, and MCH Title V Block Grant.

(Source: Coughlin TA, Holahan J, Caswell K, McGrath M. Uncompensated Care for the Uninsured in 2013: A Detailed Examination. Menlo Park, CA: The Henry J. Kaiser Family Foundation, 2014. Available at http://kff.org/uninsured/report/uncompensated-care-for-the-uninsured-in-2013-a-detailed-examination/.)

hospitals through indirect medical education (IME) funds. Anticipating that the amount of uncompensated hospital care will decrease as health insurance coverage under the ACA expands, the ACA is scheduled to reduce DSH payments to hospitals over time.

The other major governmental sources of safety net funds come from state and local government, the VA, and grants including those provided by the Indian Health Service and by the Health Resources and Services Administration to support community health centers.

Uncompensated care that is not covered by government sources may be partially subsidized by providers shifting excess payments relative to actual costs available from patients covered by private insurance to underwrite the expenses of uninsured or underinsured patients unable to fully cover the costs of their care. Providers may also receive philanthropic contributions or the in-kind contributions of volunteer health-care workers who can help furnish services to uninsured and underinsured patients.

Safety Net Hospitals

Public hospitals and some nonprofit hospitals serve as the backbone of the safety net hospitals that provide a disproportionate share of the care to vulnerable populations. Among the approximately 5700 registered hospitals in the United States, approximately 1000 are public hospitals.[24] The public hospital commitment to caring for all persons is a key attribute that makes them such an integral part of the US health-care safety net.

Many nonprofit hospitals also contribute to the care of vulnerable populations. In urban areas, nonprofit teaching hospitals are often the only providers of certain types of specialized care that typically do not generate revenues to cover their cost, such as trauma care and burn units. In rural areas, nonprofit hospitals often serve as the primary source for both ambulatory and acute care for their communities.

Current market forces are increasing the fragility of the financial sustainability of safety net hospitals. Many safety net hospitals, in fact, are operating in the red, incurring more expenses than revenue received. Some analysts have raised concerns that the new insurance payments that result from the ACA reforms will not be enough to offset the DSH reductions.[25] This will place new strain on safety net hospitals' finances and many will struggle to maintain their mission of providing high-quality hospital services to all.

Community Health Centers

The Federally Qualified Health Center (FQHC) program is the main federal policy initiative which supports the furnishing of primary care services for vulnerable populations. FQHCs are nonprofit, free-standing clinics, located in medically underserved areas, providing primary care regardless of ability to pay, and governed by a community board. FQHCs provide enabling services such as on-site availability of medications, transportation, translation services, or in-house lab testing in order to lower access barriers to care. Community health centers, migrant health centers, health care for the homeless programs, and the public housing[26] primary care programs all fall under the FQHC designation.

In 2012, a total of 1200 FQHCs served 22 million patients.[27] More than 90% of patients were from low-income families, 36% were uninsured, 39% were Medicaid recipients, and 73% were from racial/ethnic minorities. ACA and the American Recovery and Reinvestment Act (ARRA) 2 years prior provided significant funding for both FQHC organization expansion and capital funding—through 2015. By this time, it was expected that most of FQHC patients would be covered either by Marketplace plans or the mandated Medicaid expansion. FQHCs in states not opting to expand Medicaid coverage will face significant financial threats without an additional funding source.

Emergency Departments

Emergency departments (EDs) are often the provider of last resort for vulnerable populations with limited to or no access to primary care physicians and specialists. ED visits account for 10% of ambulatory care in the United States.[28]

The Emergency Medical Treatment and Active Labor Act of 1985 (EMTALA) guarantees screening and stabilizing treatment in the ED regardless of the patient's ability to pay (see Chapter 4). The requirements under EMTALA in combination with inadequate access to primary care in many communities contribute to higher use of the ED as the site of care by vulnerable patients. In 2012, the percentage of individuals with at least one ED visit was 40% among adult Medicaid beneficiaries and 25% among children covered by Medicaid as compared with 20% among uninsured adults, 16% among uninsured children, 15% among privately insured adults, and 13% among privately insured children.[29]

After losing health insurance sponsored by his employer, Mr. Walsh purchases a new insurance plan on the health insurance exchange (healthcare.gov) and receives a tax credit to defray the costs of his premium. His diabetes and hypertension did not increase the cost of the premium, because the ACA precludes insurers from increasing rates due to preexisting conditions. He and his family take advantage of the preventive care benefits in their new insurance policy and obtain flu shots and cancer screening tests, such as Mr. Walsh's colonoscopy. His primary care physician based at a community health center identifies that Mr. Walsh has proteinuria and renal insufficiency. He refers Mr. Walsh to a nephrologist, but the wait for a new appointment is 7 months. The primary care physician believes Mr. Walsh needs to be seen more urgently, but there are no other nephrologists in his local community who agree to see him any sooner.

Health Workforce

The National Health Service Corps (NHSC)[30] is one of the main federal programs recruiting providers to work in medically underserved communities by providing direct financial incentives. The NHSC aims to attract these providers through two programs: a loan repayment program and a scholarship program, both of which provide financial aid to students or practitioners of primary care disciplines in exchange for terms of service in a Health Professional Shortage Area (HPSA). Currently, there are approximately 9200 NHSC clinicians consisting of allopathic or osteopathic physicians, dentists, mental health professionals, nurse practitioners, nurse midwives, and physician assistants.[30] NHSC received significant funding increases through the ACA and ARRA. However, there are many more sites requesting NHSC clinicians, and many more clinicians applying for NHSC loan repayment, than positions funded by the NHSC.

Private physicians contribute to safety net care by providing charity care or volunteering in safety net clinics. Private physicians' offices receive no direct subsidies for unreimbursed care. Charity care in private physicians' offices is not necessarily available for all patients. Although most primary care physicians are willing to accept uninsured patients, their payment policies vary widely and may make care inaccessible. Some physicians are unwilling to accept patients with Medicaid insurance, citing low reimbursement, paperwork burden, and the medical and social complexity of cases as primary reasons. Approximately half of generalists and specialists in one survey cited additional risk of being sued as a factor in the decision to not serve uninsured and Medicaid patients,[31] although low-income patients are not in fact more likely to file malpractice claims.

Not surprisingly, physicians find it difficult to refer uninsured and Medicaid-eligible patients to specialists. Both general internists with private offices and providers at FQHCs say it is very difficult to obtain needed medical services beyond what can be provided at the office visit for their uninsured patients. Many physicians believe they must rely upon personal relationships as opposed to formal processes to connect the uninsured to needed specialty care.[32,33] Also, a quarter of the physician faculty members at US academic health centers report that they were rarely able to provide nonurgent admissions for their uninsured patients, and for some respondents, there were formal policies limiting care to uninsured patients at their institutions.[34]

CONCLUSION

The organization and financing of health care for vulnerable populations is characterized by complexity and fragility. The United States lacks a coordinated system to pay for and provide health-care services to all its residents, which leaves those most vulnerable to lack of health care in a precarious position if they lose insurance coverage or need to obtain specialized services. Although the ACA is reducing the number of uninsured Americans, it is unlikely to completely eliminate uninsurance as a problem, particularly if states choose not to expand their Medicaid programs. Moreover, low-income individuals' insurance benefits may provide protection against catastrophic loss but may not provide adequate coverage for routine and lower cost services, which leads to delays in obtaining needed care.

Safety net providers will benefit from the ACA's effects on increasing rates of insurance coverage, but only if those newly insured have policies that provide adequate reimbursement to providers. Many public hospitals are at risk of closure because of dwindling revenue sources. Despite expansion of the federal community health center program and the NHSC, there are not enough primary care safety net providers in this country to address all health needs of vulnerable populations. Because of their hands-on experience in health care, health professionals are in a unique position to advocate for strategies that will bolster the safety net and address the needs of the most vulnerable in our society.

Health System Financing
- Risk pooling is required to protect individuals from the unpredictability of severe illness
- Differs based on revenue source

Insurance Programs differ based on sources of revenue and eligibility
- Employer-sponsored insurance
- Individually purchased insurance
- Health insurance exchanges (Marketplaces)
- Medicare
- Medicaid
- CHIP

The Accountable Care Act
- Expands the risk pool through the individual mandate that requires everyone to participate in some system of insurance or pay a fine.
- Prohibits excluding patients from purchasing insurance on the basis of gender or health status (pre-existing conditions).

Safety Net Is Composed of
- Core safety net providers
- Public hospitals
- Teaching hospitals
- Federally qualified health centers
- NHSC
- Unreimbursed care
- Disproportionate share payments

Health Insurance Marketplace

- No eligibility restrictions
- Four levels of plans: bronze, silver, gold, platinum
- Tax credits available for low- and moderate-income individuals and families to lower premiums
- Other subsidies available for lowest income enrollees

Medicaid

- All states cover low-income:
  - Children under 18
  - Pregnant women
  - Working parents
  - Patients with severe physical and mental disabilities
  - Elderly low-income Medicare beneficiaries
  - Beneficiaries who receive SSI cash benefits
  - Limited eligibility for those who would otherwise be eligible (low-income pregnant women or children) but who are undocumented persons or short-term (<5 years) residents
  - Median maximum income is 50% of federal poverty line for those without employer-sponsored or privately purchased health insurance

DISCUSSION QUESTIONS

1. As a primary care practitioner, if Mr. Walsh were your patient who became newly uninsured, what would you do? How would you advocate for his need for a specialty consultation?
2. Who are the safety net providers in your community? What local funds or programs exist to support your safety net providers?
3. As providers, one of the ways to help your vulnerable patients is to get involved in advocacy. What safety net related issues can a provider be involved in at the organizational, city/county, state, or federal levels?

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Chapter 4

Legal Issues in the Care of Underserved Populations

Sara Rosenbaum, JD

Objectives

- Summarize the basic elements of the legal environment for health-care delivery for medically underserved populations in the United States, including the Affordable Care Act.
- Identify the major laws and legal concepts that govern health-care organization, financing, and delivery of health care for medically underserved populations.
- Describe the basic legal duties of health-care providers toward individuals and patients.
- Review laws that prohibit discrimination in health care.
- Review concepts of health-care quality and patient rights applicable to all patients regardless of economic or personal circumstances.

INTRODUCTION

Understanding the laws and regulations governing the care of medically underserved populations is critical for clinicians serving these patients. Federal and state laws address barriers to health care and create a legal duty to furnish health care under limited circumstances. The law also shapes and drives the public and private health insurance arrangements that pay for most health care, including care delivered to low-income and vulnerable populations.

This chapter examines three major bodies of US law that govern health-care practice for medically underserved populations: (1) access to health care; (2) insurance coverage for low-income populations through Medicaid and state health insurance exchanges; and (3) health-care quality and patient rights.

ACCESS TO HEALTH CARE

John Pool is a person with human immunodeficiency virus (HIV). He is struck by a car and is brought by ambulance to the closest trauma center, bloodied and semiconscious. His partner, who accompanies him to the hospital, explains that John is HIV positive. Hospital personnel advise John's partner that John would be best served if—rather than receiving care at their facility—the partner were to drive John to the public hospital 20 minutes away, given its expertise in caring for persons with HIV.

HEALTH CARE AS A LEGAL RIGHT

Whether there is a right to health care has long been a subject of debate in the United States, a nation that places significant emphasis on the concept of individual legal rights. This cultural emphasis on individual rights is exemplified, of course, in the US Constitution's Bill of Rights, which defines the legal relationship between individuals and government. The right to health care is not among the rights set forth, although some legal scholars have attempted to argue that the right to health care at least to preserve life should be considered an element of constitutional due process.

The Affordable Care Act (ACA) moves the United States significantly toward a system of national health insurance, although one made up of disparate sources of coverage (Medicare, Medicaid, employer-sponsored group plans, and coverage bought on an individual basis) and not subject to any uniform regulatory scheme governing cost, access, and quality. In addition, the US health-care system continues to rest on a fundamental value of freedom—one in which people remain free to say "no" to coverage (although potentially risking a tax penalty) and in which, with an extremely limited exception, health-care providers remain free to select the patients they will treat, considering factors unrelated to the need for health care.

Other nations tend to approach the bond between citizens and government somewhat differently. Laws governing universal health systems in other wealthy nations are based on the assumption that the entire population will be included in the national health-care system (e.g., the British National Health Service, Canada's Medicare program, or the regulated multipayer systems found in Switzerland or Israel). Unlike the United States, these nations have introduced uniform cost controls in order to maintain population-wide coverage without excessive expenditures. Similar to the United States, on the other hand, these nations overwhelmingly depend on private providers to care for residents, although these nations also supplement private resources with clinical providers organized and located in medically underserved communities.

The laws of a nation are a reflection of its core values. In the United States, the autonomy of the medical profession has been honored above the right of health care for individuals. Under basic principles of common law (the core system of judicial principles on which US health law rests), individuals have no legally enforceable right to health care, and health professionals and health-care institutions have no corresponding legal duty to provide care.[1] The autonomy of the medical profession is also codified in the American Medical Association's (AMA)'s code of ethics, which specifies that "a physician shall … except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care."[2]

However, these core common law principles have been overridden by states and Congress, in certain limited respects. For example, some states require hospitals to provide emergency care to their communities as a basic condition of licensure. Furthermore, since 1986, Congress has required all Medicare-participating hospitals (i.e., receiving federal funds) with emergency departments (EDs) to furnish screening and stabilization services to individuals who come to the hospital seeking treatment for emergency medical conditions.[1] This obligation is known as The Emergency Medical Treatment and Labor Act (EMTALA).[2]

Federal civil rights laws (and potentially human rights laws in many states) also protect the rights of individual patients. Civil rights laws may bar health-care providers from discriminating on the basis of race, ethnicity, language, and disability, and sex. Some states go further and bar discrimination based on gender identity or sexual orientation. But with the exception of federal regulations implementing the Hill Burton Act (discussed later), no federal law ever has barred discrimination explicitly on the basis of either poverty or an individual's status as a publicly insured person.

In the case example, both EMTALA and civil rights laws that bar discrimination against qualified individuals with disabilities come into play when an HIV-infected person seeks emergency care from a hospital. Indeed, the example is drawn from an actual incident that came before a federal court in Ohio,[3] which held that the hospital was obligated to treat the individual on grounds related to both EMTALA and the Americans with Disabilities Act (ADA), which bars discrimination by public accommodations (including health-care providers) against qualified persons with a disability.[3] Indeed, the ADA applies even in nonhospital health-care settings, because health care is considered a "place of public accommodation"[4] that must be open to all persons who can meet the basic requirements for care (i.e., who are able to pay). For example, in a case involving a dentist in private practice who refused to fill a cavity for an asymptomatic HIV-positive patient citing personal safety concerns, the US Supreme Court held that asymptomatic HIV constitutes a disability under the ADA and that as places of public accommodation, office-based health-care providers could not refuse service in their offices to HIV-positive patients who could pay for services, unless the provider could prove that such a patient poses a direct threat. (In this case, the dentist could not prove his claim).[4]

IMPACT OF RACE AND ETHNICITY

The Court's 1954 landmark decision in Brown v. Board of Education[5] ultimately permeated all aspects of public life, including the South's legally segregated health-care system.[6,7] Although legally sanctioned racial segregation ended by the mid-20th century, significant health disparities based on race and ethnicity persist. Research suggests that vestiges of racial and ethnic discrimination are displayed in the attitudes and beliefs of health professionals and the culture of clinical practice.[6] In a legal context, these attitudes and beliefs potentially (today, thankfully rarely) can show up as intentional discrimination (e.g., refusing to treat a patient because of the color of her skin). But legal discrimination also can flow from "facially neutral" policies and practices (such as where to locate a hospital) that on the surface have nothing to do directly

with race or national origin but that can have a discriminatory impact. For example, institutions sometimes segregate Medicaid beneficiaries (who disproportionately are members of racial or ethnic minority groups) into separate hospital or nursing home wings, or separate managed care provider networks. The intent is to segregate by insurance status, but the impact falls disproportionately on minority patients.[8]

The refusal of health-care providers to participate in Medicaid (typically because of low payment levels) has long served as a de facto means of perpetuating racial discrimination in a clinical practice, because of the disproportionate dependence on the program by minority patients.[9]

IMPACT OF POVERTY

The example of Medicaid nonparticipation also illustrates the often-intertwined nature of race and poverty where health-care segregation and exclusion are concerned. Poor persons, who are disproportionately members of racial and ethnic minority groups, are far more likely to be uninsured or publicly insured.[10] Yet federal civil rights laws do not recognize poverty as a suspect classification that can trigger a finding of discrimination. Furthermore, even where federal civil rights laws might reach de facto discrimination (e.g., not taking Medicaid because of low payments, which in turn falls more heavily on minority patients), the law also gives defendants in civil rights cases a "business necessity" defense[11] to a claim of discrimination, meaning that as a legal matter even if discrimination is shown, the availability of such a defense makes it impossible to win a case. An important feature of the ACA was aimed at expanding access to care in Medicaid and included the provision that temporarily increased Medicaid fees for primary care to Medicare payment levels. Following expiration in 2014, the provision was not extended.

STATUTES GOVERNING HEALTH-CARE ACCESS

THE EMERGENCY TREATMENT AND LABOR ACT

The Emergency Treatment and Labor Act (EMTALA) creates a legally enforceable right of access to certain services furnished by Medicare-participating hospitals with EDs (the vast majority of US hospitals). EMTALA applies to all persons regardless of health insurance status, legal US status, income, or other personal characteristics.[12] Many states have laws that parallel EMTALA requirements and that may apply to all licensed hospitals regardless of their Medicare participation status.

Table 4-1. EMTALA: COBRA Requirements

The Hospital

- Provide a medical screening examination to all patients who seek emergency care within 250 yards of the hospital's main buildings.
- Stabilize the patient's condition if necessary or arrange a medically appropriate transfer if the patient is unstable.
- Maintain an accurate list of specialty physicians on call to stabilize emergency patients.
- Provide medically appropriate transfers of unstable patients.
  - Complete transfer form, weighing risks and benefits of transfer.
  - The patient may request transfer by written request.
  - The patient must have an accepting physician.
  - There must be written consent from the patient to transfer.
  - The transfer must be by appropriate medical vehicle.
  - There must be qualified transport personnel to meet the level of care needed by the patient.
  - Copies of medical records and x-rays must be sent with patient.

Source: Adapted from Mantini SL. What's EMTALA, and what are its implications? ENA EMTALA Work Group. Emergency Nurses Association. Available at http://www.ena.org/government/emtala/article1.asp.

EMTALA was enacted to stop the practice of "patient dumping," that is, turning away or prematurely discharging people in need of hospital care. Medical indigence is often the basis for these practices, but as the opening case example illustrates, patient dumping takes place for reasons that can go beyond the inability to pay for care.

EMTALA is complex and nuanced; at the same time, however, EMTALA establishes certain fundamental requirements that together impose an unprecedented enforceable legal right to screening and stabilization care on the part of individuals who seek emergency care from a covered hospital. EMTALA creates two basic hospital duties (Table 4-1).

The Duty to Provide an "Appropriate" Medical Examination

Hospitals must provide an "appropriate" examination to an individual who "comes to" a hospital's "dedicated ED" seeking care for an "emergency medical condition" (42 U.S.C. §1395dd(e)(1)(A)). The concept of "comes to" can include persons who are not yet physically inside the ED but who are on the grounds of the hospital or in reasonable proximity, as well as people who are being transported to a facility by ambulance (42 C.F.R. §489.24). A "dedicated ED" can include not only the actual ED but other parts of a hospital that function as EDs a majority of the time (e.g., a hospital's off-campus outpatient facility) (42 C.F.R. §489.24). An "appropriate" examination means one that is nondiscriminatory and that adheres to the hospital's emergency examination protocols (42 C.F.R. §489.24).

Under EMTALA, an "emergency medical condition" means a "medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain)

such that the absence of immediate medical attention could reasonably be expected to result in (a) placing the health of the individual (or, with respect to a pregnant woman, the health of the woman or her unborn child) in serious jeopardy; (b) serious impairment to bodily functions; or (c) serious dysfunction of any bodily organ or part" (42 U.S.C. §1395dd(e)(1)). This definition presumably would include psychiatric disturbances that present a risk of serious physical injury to either the patient or another person regardless of whether or not psychiatric services are provided by the hospital.

The Duty to Provide Stabilization Care

The second EMTALA obligation is the duty to stabilize an emergency condition. In cases in which a patient cannot be stabilized with existing hospital resources, a hospital can, under carefully controlled circumstances, effectuate a medically appropriate transfer of an unstable patient. A medically appropriate transfer is one that is conducted in a medically appropriate manner, and in which a personal certification by a physician at the transferring facility that the benefits of the transfer outweigh its risks and a receiving institution has agreed to accept the transfer (42 U.S.C. §1395dd(b)). "Stabilized" is defined as meaning "that no material deterioration of the [emergency medical] condition is likely, within reasonable medical probability, to result from or occur during the transfer of the individual from a facility" (42 U.S.C. §1395dd(e)(3)). In the case of a pregnant woman having contractions, the concept of medical emergency means "that there is inadequate time to effect a safe transfer to another hospital before delivery, or that transfer may pose a threat to the health or safety of the woman or the unborn child" (U.S.C. §1395dd(e)(1)).

Potential Consequences of an EMTALA Violation

Violation of EMTALA can result in a hospital's exclusion from Medicare, as well as serious financial sanctions imposed on both the hospital and its physicians. In addition, both individuals and hospitals that are "dumped on" have explicit rights under the law and can sue offending hospitals to vindicate those rights (42 U.S.C. §1395dd(d)). In the example of Mr. Pool, the hospital's effort to turn away an HIV-positive patient without furnishing a medical examination and either necessary stabilization or a medically appropriate transfer raised a potential EMTALA claim. In addition, had his partner driven Mr. Pool to a public hospital that accepted the case, that hospital might have a claim against the "dumping" facility (Box 4-1).

Box 4-1. Examples of Confirmed and Potential EMTALA Violations

Nature of Violation	Examples
Failure to provide appropriate transfer and keep log	• A bicycle accident victim was transferred without a screening exam or entry into the central log. The hospital told the rescue crew that the patient should go to another hospital because he met trauma criteria when he did not meet the criteria. The hospital also did not contact or send records to the receiving hospital.
Failure to screen, stabilize, and keep log	• A patient with end-stage renal disease was discharged without being stabilized and died 6 hours later. • A motor vehicle accident victim was not stabilized and became paralyzed in the emergency room. • An uninsured patient with suicidal symptoms was put into a taxi for transfer to another hospital without being examined. • An insured patient with a rash received screening while an uninsured patient with the same symptoms was sent to a clinic without screening. • A patient from a skilled nursing facility was diagnosed with pneumonia and medicated but sent back to the skilled nursing facility without a physician determination that he was stable; he returned later in worse condition and died.
Failure to meet receiving responsibilities, follow procedures, and provide appropriate transfer	• A hospital refused to accept transfer of an unstable patient with multiple traumas from a motor vehicle accident. • A possible sexual assault victim who arrived in an ambulance was sent to another hospital without screening, and there was no evidence in the record that the receiving hospital was notified or had agreed to accept the patient.
Refusal to accept a patient coming to the hospital in a community ambulance	• A hospital cannot refuse patients coming to the facility in a community ambulance unless it is on formal diversion status.

Adapted from United States General Accounting Office Report to Congressional Committees. EMERGENCY CARE. EMTALA: Implementation and Enforcement Issues. Washington, DC: GAO-01-747, June 22, 2001; Rosenbaum S. The enduring role of the Emergency Treatment and Active Labor Act. Health Aff (Millwood) 2013;32: 2075-2081; Rosenbaum S et al. Case studies at Denver Health: 'patient dumping' in the emergency department despite EMTALA, the law that banned it. Health Aff (Millwood) 2012;31: 1749-1756.

CIVIL RIGHTS LAWS

TITLE VI OF THE CIVIL RIGHTS ACT OF 1964

The 1964 Civil Rights Act is one of the great landmarks in US law. The Act (Title II) establishes civil rights protections in "places of public accommodation" such as restaurants, hotels, and public transportation systems. Unlike the ADA, however, health-care providers were not classified as public accommodations in 1964; such an effort would have quite literally sunk the law given the widespread segregation that still prevailed in the South and the power of Southern Members of Congress over the measure. Instead, the Civil Rights Act reached health care through a separate Title VI, which broke new ground by prohibiting discrimination based on race or national origin by "recipients of federal assistance" (42 U.S.C. §2000d (2004)) and then by classifying federal health and health-care financing programs as "federal assistance." Despite this advance, when Medicare was enacted in 1965, an agreement was reached (nowhere evident in the statute itself)[12] that Medicare Part B (physician payment) would not be treated as federal financial assistance. Physicians who do not participate in any federal programs or whose only participation is in Medicare Part B on a non-assignment basis are not subject to Title VI of the Civil Rights Act. The federal government, as of spring 2014, classifies qualified health plans as federally assisted entities for purposes of Title VI and certain other federal civil rights laws.

Under Title VI, the concept of "discrimination" covers both acts of intentional segregation and exclusion, as well as practices that have the effect of subjecting persons to segregation and exclusion. Because of a US Supreme Court's decision issued in 2001, private individuals can sue to remedy intentional acts of discrimination, but only the federal government can enforce the de facto (i.e., effects) test.[13]

Conduct that might be considered as potentially in violation of the de facto test would be segregating hospital or nursing home patients by source of payment (e.g., maintaining an "all-Medicaid" floor or wing, a problem that actually has arisen in both hospital and nursing home settings).[12] Another example would be a health maintenance organization (HMO) that enrolls both privately insured and Medicaid-insured persons but that offers different provider networks based on payer status or that, in the case of an HMO that uses a single network, allows some of its specialists to refuse to accept Medicaid patient referrals (an often-rumored practice).

The Department of Health and Human Service's (HHS) Office for Civil Rights has issued guidelines that require federal assistance recipients to make their services accessible to patients with limited English-speaking abilities.[14] The guidelines offer a range of compliance approaches for providing both oral and written interpretation and translation services. Federal recipients decide which services to provide by using a four-factor test that weighs the number of limited English people served, the frequency they come into contact with a particular program or service, the nature and importance of the activity, and the resources available. In addition, the guidelines provide incentives for compliance by permitting affected organizations to secure certification of compliance. Facilities considered by HHS to comply with the law have an additional and strong defense when individuals file complaints about the lack of services accessible to persons with limited English-speaking abilities.

THE AMERICANS WITH DISABILITIES ACT

> James Geary, a pediatrician in private practice, decides to reduce his caseload as he approaches retirement. When deciding which patients he will continue to see, he first considers finances. He will no longer provide care to any Medicaid or uninsured children because they do not pay his full rate. In addition, he decides to eliminate several children with autism and Tourette syndrome because he does not like to be around their outbursts and unusual movements.

Dr. Geary can pick the insurance plans in which he will participate. But the ADA and its companion, Section 504 of the Rehabilitation Act (29 USCA §794 (West 2014) may bar him from refusing to treat children with certain types of disabilities. The ADA prohibits discrimination against qualified persons with disabilities. As with Title VI, the ADA reaches both private and public conduct and both intentional discrimination and de facto conduct that result in discrimination. Unlike Title VI, however, the ADA reaches conduct not only by entities that receive federal financial assistance (e.g., hospitals that accept Medicaid) but also private actors who receive no public funds. Thus, in Bragdon v Abbott,[4] a dentist in private practice was found liable for an ADA violation by refusing to treat an HIV-positive patient who offered to pay cash for care.

Under the ADA, a disability is defined as a physical or mental impairment that significantly affects functioning in one or more areas of life activities (certain limitations apply, particularly in the employment context) (42 USCA §12101–12213). A "qualified individual with a disability" is a person who meets the requirements of the service or the program, with or without provision of any reasonable accommodations to make the program accessible. For example, a person who receives Supplemental Security Income (SSI) cash assistance for a disability is automatically qualified for Medicaid and thus is entitled to ADA protections against discriminatory treatment by Medicaid

agencies. Similarly, an SSI recipient with a serious mental disability who lives in a community health center's service area is considered to meet the center's eligibility rules and therefore cannot be denied the center's services because he or she has a mental disability. Likewise, states cannot administer Medicaid in ways that effectively confine persons with disabilities to medically unnecessary institutional settings as a condition of coverage.[15]

LEGAL OBLIGATIONS OF HILL BURTON FACILITIES

The Hill Burton Act (whose official title is the Hospital Survey and Construction Act of 1946) financed the construction and modernization of thousands of health-care facilities. In exchange for the receipt of federal funds, facilities promised to provide a reasonable volume of uncompensated care to persons unable to pay (the uncompensated care obligation), as well as to serve the communities in which they were located (the community service obligation) (42 U.S.C. §291 et seq). Hill Burton is the only US nondiscrimination law that ties its prohibitions to low socioeconomic status as well as other personal factors such as race or disability.

The Hill Burton program's uncompensated care obligation was time limited, and all such obligations have now expired. However, the community service obligation is perpetual; as a result, its provisions are still applicable.[12] Under the community service obligation, facilities must furnish emergency care without regard to ability to pay (an obligation that parallels the later EMTALA legislation). More significantly, Hill Burton facilities are prohibited from discriminating in the provision of services on the basis of public insurance status. Therefore, facilities built with Hill Burton funds must make their services accessible to Medicaid beneficiaries.

LAWS THAT FINANCE HEALTH CARE FOR MEDICALLY UNDERSERVED POPULATIONS

Federal and state governments have enacted laws to provide for investment in public health-care programs. Laws that authorize direct expenditures for health care also carry obligations for the entities that receive grant funds or payments. These obligations typically are enforceable by public oversight agencies but not individual patients. Examples of such laws are state and local laws authorizing the establishment and funding of public health agencies, state and local laws that create public hospitals and "health-care districts," and federal laws authorizing the expenditure of funds to establish and operate health-care clinics such as the community health centers program. Examples of obligations connected to the receipt of grant funds are the obligations contained in most programs authorized under the Public Health Service (PHS) Act programs. For example, clinics that receive funding under the PHS Act such as community health centers, federal family planning programs, or the Ryan White Care Act serving persons with HIV/AIDS must serve Medicaid patients. See, for example, 42 U.S.C. §§254d-254c-18 (2004)) (health centers). PHS Act grantees are among the nation's most important sources of health care for Medicaid beneficiaries. In 2011, for example, health centers served more than 8 million Medicaid beneficiaries, or more than one in seven Medicaid beneficiaries nationally.[16]

Federal and state laws creating and financing the actual provision of health care typically share a number of common features, such as an obligation to serve certain populations or communities, an obligation to provide certain specific services as a condition of funding, and an obligation to serve low-income people free of charge or for an income-adjusted fee. Community health centers, whether federally funded or "look-alike" health centers that do not receive federal grant funds (both types of health centers are treated as "federally qualified health centers" for purposes of payment under federal insurance programs) have a unique obligation to govern their operations using community boards with a majority of its members being actual patients of the health center.

MEDICAID: HEALTH-CARE FINANCING FOR THE POOR

MEDICAID'S ROLE

Medicaid is unique among US laws with respect to the rights that it confers on poor and medically underserved populations and the corresponding obligations it imposes on states that choose to participate in Medicaid. Thus, an understanding of the basic elements of Medicaid's eligibility and coverage requirements are critical to the provision of care for vulnerable populations (Figure 4-1). This is especially true in the wake of the Patient Protection and Affordable Care Act (commonly referred to as the Affordable Care Act), which transforms federal Medicaid eligibility standards by expanding coverage to all nonelderly adults who are citizens or long-term legal residents and whose incomes are at or below 138% of the federal poverty level (about $15,000 for a single person in 2014). (42 U.S.C. §1396a(a)(10)(A)(i)(VIII). At the same time, in its landmark decision on the constitutionality of the ACA, NFIB v Sebelius,[17] the US Supreme Court allowed states to opt out of the Medicaid expansion. By fall 2015, 20 states have made an opt-out decision, affecting some 5 million low-income Americans, a disproportionate percentage of who are African American and reside in the South. (By fall 2015, the number of participating states had risen to 30 plus the District of Columbia).[18]

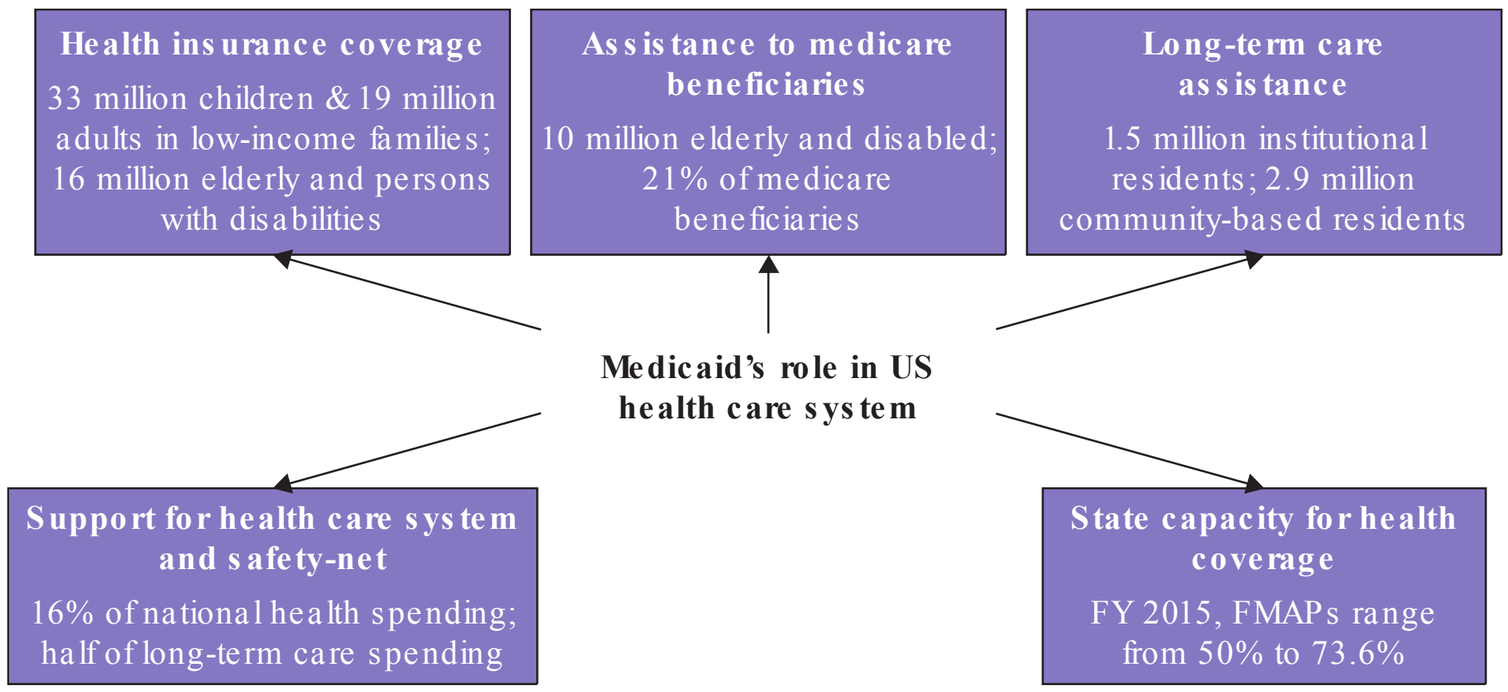


Figure 4-1. Medicaid's Role in US Health-Care System. Medicaid coverage facilitates access to care for beneficiaries, is a core source of financing for safety-net hospitals and health centers that serve low-income communities, and is the main source of coverage and financing for nursing home and community-based long-term care. Overall, Medicaid funding supports about 16% of total personal health spending in the United States. FMAP, Federal Medical Assistance Percentage. (States and the federal government share the cost of Medicaid. The federal match rate is known as the FMAP.) (Adapted from Paradise J. Medicaid Moving Forward. Kaiser Family Foundation Issue Brief Mar 09, 2015. http://kff.org/health-reform/issue-brief/medicaid-moving-forward/.)

ELIGIBILITY FOR MEDICAID

Financial Eligibility and Eligibility Categories

Traditionally, states that participate in Medicaid (all states have done so since 1982) have been required to cover certain basic categories of low-income persons: low-income children younger than 18 years with family incomes up to 138% of the federal poverty level[19]; low-income pregnant women with incomes up to 138% of the federal poverty level; parents and caretaker relatives of "dependent" children younger than 18 years, who satisfy a state's financial eligibility standard (which in many states is less than 50% of the federal poverty level, a figure that remains significant in states that have opted out of the nonelderly adult expansion); and children and adults who receive SSI benefits (42 U.S.C. §1396a(a)(10)(A))(i)). Medicaid also gives states the power to extend coverage to children and adults with serious disabilities, even if they already have either employer coverage or Medicare.

The ACA expanded federal Medicaid eligibility standards to include all adults aged 19–64 years with family incomes up to 138% of the federal poverty level (42 U.S.C. §1396a(a)(10)(A)(i)(VIIII)). The nationwide effect of this expansion would have been dramatic, adding coverage for some 17 million uninsured poor nonelderly adults estimated to meet the Medicaid expansion criteria.[20] These newly eligible adults consist of parents of minor children whose incomes exceeded states' exceptionally low poverty standards for parents, as well as other nonelderly adults without minor children who are neither pregnant nor persons with disabilities (e.g., a 62-year-old woman who works full time at the minimum wage and has a 34-year-old daughter).

Breaking with decades of legal precedent, however, the Supreme Court ruled in NIFB v Sebelius that requiring participating states to extend coverage to all low-income adults as a basic condition of participation in the traditional program was unconstitutional and that states had to be given the ability to opt out (the decision best known for upholding the constitutionality of the ACA's so-called personal responsibility requirement). The effect of its ruling was to make the adult Medicaid expansion group optional. Its impact on insurance coverage has been breathtaking.

By fall 2015, a total of 30 states and the District of Columbia had opted into the Medicaid expansion and had extended coverage to low-income adults. The states that had opted out as of this date accounted for 4.8 million poor adults who would have been covered had their states expanded. Two states alone—Florida and Texas—accounted for 38% of all adults denied coverage because of this opt-out decision. Uninsured low-income African-American adults comprised 40% of the adult population falling within the coverage gap.[21] In the opt-out states, the 2013 median eligibility standard for parents of minor children stood at 47% of the federal poverty level ($9200 for a family of three), while in some of the states that had opted, the eligibility standard for parents was less than 20% of the federal poverty level. For adults without minor children who are neither pregnant nor disabled, eligibility for Medicaid does not exist at any income level in these states. Eligibility for premium tax subsidies toward the cost of coverage through qualified health plans sold in health insurance exchanges (established under the ACA) does not begin until household income reaches 100% of the federal poverty level. This means that poor adults in

Medicaid opt-out states fall into a coverage gap and will be denied assistance completely.[22]

Special attention should be given to patients who are poor Medicare beneficiaries. This is because millions of low-income Medicare beneficiaries (including all beneficiaries who receive Supplemental Security Income [SSI] cash benefits) are also entitled to Medicaid. SSI recipients receive full Medicaid coverage, while low-income Medicare beneficiaries not entitled to SSI are entitled to Medicaid assistance with Medicare's premiums, deductibles, and cost sharing. Medicare beneficiaries who are also entitled to Medicaid are known as "dual eligibles."[23] and may qualify for either full Medicaid coverage or partial coverage for Medicare premium and cost-sharing help. Medicaid covers many services that are not covered by Medicare. Also, as noted, Medicaid will pay the Medicare premium and deductible (and in some cases, the coinsurance). As of January 2006, when Medicare's Part D outpatient prescription drug coverage benefit took full effect, outpatient prescription drug coverage is no longer a Medicaid benefit for Medicare beneficiaries who also receive Medicaid. Instead these "dual eligibles" are enrolled in Medicare Part D outpatient prescription drug plans and receive special subsidies (known as low-income subsidies)[24] to help with the cost of Part D coverage.

State Residency

Medicaid eligibility depends on being able to prove residency in the state in which coverage is sought. State residency status is frequently cited as a barrier to Medicaid enrollment. It is important to remember that states cannot demand a permanent home address as a condition of eligibility, and thus cannot deny coverage to otherwise eligible homeless persons.[25] Similarly, migrant workers are considered to be residents of the state in which they are working or seeking work, and therefore can apply for coverage even as they travel.[25] A state with a large migrant population also can provide coverage on an out-of-state basis as families travel, just as private insurance can offer out-of-state coverage (see Chapter 29).

Legal US Status

> Miriam Rodriguez has no legal US status and has been in the country for 4 years. She is pregnant. She has no health insurance and comes to your clinic for prenatal care. She has a number of health complications that will require that she receive specialty care during the pregnancy, and you already know that she will need a scheduled caesarean section delivery. You want her to enroll in Medicaid now in order to have a means to manage her specialty and inpatient care, including preregistration for delivery. You are deeply concerned about the quality of care she will be able to receive from you in the absence of coverage.

Eligibility for Medicaid is also tied to citizenship or legal US status. Legal status is one of the thorniest issues in Medicaid. The 1996 welfare reform legislation significantly restricted Medicaid eligibility for legal immigrants.[26] Persons who are otherwise eligible for benefits (e.g., low-income children, low-income pregnant women, low-income adults), but who are undocumented persons or short-term (<5 years) legal residents, are entitled to coverage only for emergency care.[27] States can waive the waiting period for pregnant women and children under both Medicaid and CHIP, and as of 2014, 22 states had done so.[27] However, short-term legal US residents barred from Medicaid because of its special waiting period are entitled to premium subsidies for coverage through their state's health insurance Exchange, even if their incomes are below the Exchange income threshold of 100% of the federal poverty level. ACA §1401 (Note that in states that expand Medicaid, the Exchange income threshold rises to 138% of the federal poverty level, the point at which Medicaid eligibility ceases.).

The problem of status as a "public charge" is a very serious one in immigration law, and has profound ramifications for eligibility in certain public assistance programs. The law defines a "public charge" as a person who is unable to support him- or herself and therefore depends on public cash assistance for income through programs such as SSI, Temporary Assistance to Needy Families, or General Assistance. Immigration officials consider whether people are likely to become a "public charge" when deciding whether they may enter the country or become permanent residents. In some instances, an immigrant may be deported if he or she becomes a "public charge" within 5 years of entry in the United States.

In an attempt to encourage Medicaid enrollment of eligible legally resident families, guidelines issued by the Department of Justice in 1999 provide that receipt of Medicaid in a noninstitutional context does not constitute evidence of being a "public charge" for the purpose of determining who will be permitted to remain in the United States.[27] Similarly, the guidelines emphasize that the use of health centers and other public clinics by immigrants does not in any way affect their legal status, because such community services are not considered to be the type of means-tested public benefits that are barred to immigrants as a result of the 1996 welfare reform amendments. Even so, because of fear and confusion about the law, many eligible immigrants do not seek health care because they do not want to risk being considered a "public charge." (see Chapter 29).[28]

Retroactive Eligibility

A final important aspect of Medicaid is that eligibility is retroactive eligibility, which allows coverage to begin up to 3 months prior to the date of application, as long as an individual would have been entitled to coverage had he or she enrolled at this earlier date (42 U.S.C. §1396a(a)(34)). As a result, patients with high medical bills may qualify

for help with these costs if the bills were incurred within this 3-month retroactive time frame.

ACCESS TO MEDICAID ENROLLMENT

Medicaid is a legal entitlement, meaning that people must be allowed to apply for coverage at any time and must be given coverage if they meet the program's eligibility standards (42 U.S.C. §1396a(a)(8)). By contrast, the Children's Health Insurance Program (CHIP), which provides coverage for low-income children whose family incomes exceed the Medicaid eligibility standard, is not a legal entitlement, and states can legally establish coverage waiting lists, which some states have done in the past.[29] (CHIP's[30] reauthorization in 2009 was accompanied by more generous funding designed to eliminate the risk of waiting lists, and in 2015 Congress extended CHIP funding for two additional years).

Persons who are found eligible for coverage must be furnished with assistance with "reasonable promptness" and have the right to remain enrolled until they are no longer eligible for coverage (eligibility cannot be arbitrarily ended) (42 U.S.C. §1396a(a)(8)). The ACA also clarifies that the "reasonable promptness" standard applies not only to medical assistance coverage but also to covered medical care services as well.

If denied eligibility, or if eligibility is terminated, individuals have the right to a "fair hearing" (42 U.S.C. §1396a(a)(4)). This fair hearing right, a basic tenet of due process, also applies if coverage is denied (e.g., if an individual is determined ineligible for continuing home care benefits or personal attendant services).

BENEFITS AND COVERAGE

> You are managing the health care of Simon, a little boy born with cerebral palsy, who has both gross motor and speech delays. You want to order physical and speech therapy for him. Medicaid insures him. The Medicaid managed care organization of which he is a member denies your treatment request, telling you that because children with cerebral palsy cannot "recover" from their conditions, the company does not consider his care medically necessary. The company tells you that when the child enters school, "the school system will have to give him something."

Medical Assistance

Medicaid beneficiaries are entitled to a comprehensive, defined set of benefits, known collectively as "medical assistance." In the case of children younger than 21 years, coverage is unusually broad, encompassing a wide array of preventive benefits (checkups, all recommended immunizations, vision, dental, and hearing care), in addition to services and treatments needed to "ameliorate" mental and physical conditions. This special set of benefits is known as Early and Periodic Screening Diagnosis and Treatment (EPSDT) (medical assistance, in 42 U.S.C. §1396d(a)(4)(B)). Simon, the boy with cerebral palsy, is entitled to coverage under EPSDT. Because EPSDT requires states to provide services to both cure and ameliorate children's medical conditions, a Medicaid agency is obligated to pay for full care for the child, even if its contract with the managed care organization allows the company to deny any services not needed to "cure" an illness or injury. Thus, a child enrolled in Medicaid remains entitled to all medically necessary EPSDT "ameliorative" care. Even if his or her managed care plan does not directly pay for the care, the Medicaid agency must do so. For this reason, appealing denials of necessary care for Medicaid beneficiaries, particularly children, is important.

Essential Health Benefits

In the case of adults, states may impose stricter coverage limits and more stringent medical necessity definitions. For newly eligible adults in states that opt into the Medicaid adult expansion (as well as children aged 6–18 years with incomes between 100% and 138% of the federal poverty level), coverage must be at the same level as provided for in the case of private health insurance sold in the individual and small group markets, including qualified health plans sold in the Exchange (42 U.S.C. §1396u-2). This special benefit standard is known as "essential health benefits (EHBs)."

The EHB package consists of 10 broadly described benefit categories that potentially offer significantly less coverage than traditional Medicaid: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care (PPACA §1302). Under federal and state regulations, health insurers have considerable discretion to impose treatment limits and exclusions on EHBs, as long as they cover some level of benefit (e.g., four habilitation treatments a year) and do not discriminate against persons with mental illness or substance use disorders (special mental health parity laws apply to beneficiaries covered for the EHB package rather than traditional Medicaid benefits).

At the same time, the EHB package for Medicaid beneficiaries is strengthened in several ways. First, all beneficiaries younger than 21 years enrolled in EHB-level coverage remain entitled to full EPSDT benefits rather than the more limited pediatric services found in the EHB package. Second, EHB-level coverage for Medicaid beneficiaries preserves free choice of providers (i.e., access to non-network providers) for family planning services and supplies. Third, nonemergency medical transportation

is preserved for beneficiaries with EHB-level coverage. Finally, the EHB package includes the same preventive services without cost sharing that privately insured adults are entitled to receive as a result of the ACA (e.g., ACIP-recommended immunizations, well-women's services recommended by the Health Resources and Services Administration; all screening and preventive treatment services recommended by the US Preventive Services Task Force) (§2713 of the PHS Act, added by PPACA §1001).

Medical Necessity

Other than EPSDT's special concepts of "early" and "ameliorate," the Medicaid statute does not define "medical necessity" (42 CFR §440.230(d)). As a result, states have attempted to narrow coverage by adopting restrictive definitions of "medical necessity." Even though adult coverage is more limited, the breadth of benefits is substantial, and state agencies are prohibited from using unreasonable benefit limits or arbitrarily discriminating against persons with specific health conditions in the provision of required benefits (42 CFR §440.230). Thus, for example, a state agency could not refuse to pay for physician services for psychiatric conditions while covering physician care for physical health problems.

As noted, the same fair hearing rules that apply to the denial of eligibility also apply to denials of specific types of coverage. Consequently, health professionals working with medically underserved populations should be energetic in protesting denials of what they consider to involve medically necessary patient treatment. Advocacy for patients encompasses locating help in appealing coverage denials (e.g., legal services, or law firms in the community that take pro bono cases) and, as importantly, providing expert-written statements or, when necessary, oral testimony about the medical necessity of prescribed care (see Chapter 8). The right to appeal denials applies regardless of whether the denial comes from the state agency itself or from a managed care organization acting on the state's behalf.

MEDICAID PROGRAMS OPERATED AS SECTION 1115 DEMONSTRATIONS

A significant number of states operate portions of their Medicaid programs under special demonstration authority. These demonstrations are known as "Section 1115 demonstrations" because of the section of the Social Security Act (§1115) in which this special demonstration authority given to the Secretary of HHS is found.

Dating back to 1962 (prior to Medicaid's 1965 enactment), §1115 empowers the HHS Secretary to waive provisions of the Medicaid statute (something that under normal circumstances a federal agency official cannot do—the law must be implemented as Congress enacts it) in order to conduct research and demonstrations that in the view of the HHS Secretary will further the objectives of the Medicaid program. In other words, once a state receives §1115 demonstration status for one or more parts of its Medicaid program, it can operate Medicaid in ways normally prohibited under federal law. In order to receive demonstration status, states must develop their demonstration proposals in a manner that permits public review and comment; likewise, the Secretary must obtain public input of a state's demonstration proposal and must decide whether to grant special waiver authority.

Receiving special §1115 demonstration status means that a state may be able to operate Medicaid in ways that depart from traditional program standards and alter significant Medicaid beneficiary protections, although the value of the demonstration is that it typically also results in coverage enhancements for other beneficiaries. For example, using §1115, states can require managed care enrollment for populations (such as children and adults with serious disabilities) who ordinarily would be exempted from a mandatory enrollment requirement. Beginning in 2013, for example, the HHS Secretary used §1115 demonstration flexibility to encourage states that might not otherwise have done so to expand Medicaid to cover all low-income adults, as called for under the ACA. This added flexibility can take several forms: charging modest premiums for adults who otherwise would not be required to pay for coverage under traditional Medicaid rules; offering fewer benefits than otherwise would be required; making higher copayments than Medicaid law permits; having cost sharing or even eligibility conditioned on satisfying certain behavioral requirements (such as enrolling in tobacco cessation or weight-loss programs); and other modifications of traditional standards.[31]

As of spring 2015, Arkansas, Iowa, Indiana, New Hampshire and Michigan were operating their Medicaid adult expansion programs under §1115 demonstration authority, and several other states that had not yet expanded Medicaid were either considering or actively seeking similar flexibility. Arkansas' §1115 demonstration is particularly notable because of the state's decision to use its demonstration flexibility to enroll Medicaid adults (other than those considered medically frail) in private insurance by purchasing coverage through qualified health plans sold in the state's exchange rather than providing them with traditional Medicaid coverage.

COVERAGE THROUGH HEALTH INSURANCE EXCHANGES

The ACA transforms the market for private health insurance coverage in the United States. In exchange for the requirement that all persons who can afford to do so

purchase or enroll in health insurance, the ACA fundamentally alters how health insurance operates, by barring insurer practices that historically kept individuals from securing any, or adequate, coverage: the refusal to sell or renew policies to people who were sick; the refusal to cover preexisting conditions; pricing practices that made coverage unaffordable for people with even mild or moderate health conditions; coverage that was in fact unaffordable in the case of illness because of harsh annual or lifetime dollar limits on covered benefits; and other practices designed to avoid or limit risk exposure to people in less than perfect health.

In addition to reforming the insurance market, the ACA establishes health insurance exchanges (whose names vary depending on the state) and offers premium subsidies and financial help with patient cost sharing to individuals and families who have too much money for Medicaid or CHIP (in the case of children), but whose incomes are low or moderate, and who have no access to affordable employer coverage. Individuals and families with household incomes between the premium subsidy assistance threshold (100% of the federal poverty level in states that do not expand Medicaid; 139% of the federal poverty level in adult Medicaid expansion states) can receive premium assistance as long as their incomes are below 400% of poverty. Cost-sharing assistance is available for individuals and families who have premium subsidies, as long as their household income is 250% of the federal poverty level or below.

Unlike Medicaid and CHIP, where enrollment is continuously accessible throughout the year, enrollment in the exchange is based on private insurance principles. This means that the exchange enrollment process is governed by formal open enrollment periods in order to guard against adverse selection, which would happen if people could enroll only when they needed medical care. Federal law permits many exceptions to open enrollment (known as special enrollment periods). The most common are the types of life circumstances that happen to people all the time and have nothing directly to do with health care: losing a job; losing prior insurance coverage; a new job that comes with no health insurance; a family life change such as a birth or a marriage or a divorce; moving to a new state; and other life events (45 C.F.R. §155.420).

Because the enrollment process is complex, enrollment assistance is available through community organizations (known as navigators) as well as virtually all community health centers, public and safety net hospitals, and other community-based settings. In some states, individuals and families may be able to enroll in a single, smooth process in which one application is filed and eligibility is assessed across "insurance affordability programs" (i.e., Medicaid, CHIP, exchange subsidies). However, in most states, enrollment may be bifurcated; that is, applicants may have to file separately for different sources of subsidies. Moreover, it is common for lower-income wage earners to experience relatively frequent income fluctuations because of changes in work hours and periods of layoff (especially seasonal workers). This problem of "churning" between Medicaid and exchange subsidies is projected to affect some 28 million adults and millions of children,[32] meaning that community-based assistance with maintaining coverage once it is secured will be essential.

HEALTH-CARE QUALITY

In general, health professionals have no legal obligation to furnish care to any person (known as no legal duty of care). Exceptions are hospital emergency care situations such as those described earlier in this chapter, or in which a provider is part of a managed care provider network and thus is contractually obligated to treat plan members. However, once a health professional accepts a patient into practice, he or she owes the patient a duty to furnish health care of reasonable quality. This duty sometimes is referred to as the "professional standard of care."

PROFESSIONAL STANDARD OF CARE

The professional standard of care guides the law of health-care quality in all states.[33] The professional standard of care is highly case specific and factually intensive. In legal proceedings involving medical malpractice claims, whether or not a health professional has satisfied the professional standard of care (and even what that standard will be in any particular case) is question of fact to be proved through the use of expert testimony as well as valid, relevant, and reliable evidence from studies and research. Failure to meet the standard of care can result in liability for injuries that are a reasonably foreseeable result of professional negligence.

The law measures professional negligence under a unitary standard of conduct and without setting different standards of care for different populations based on the availability of resources.[33] Furthermore, the failure of a health professional to "comply without protest" with a denial of coverage by a utilization review entity can result in provider liability if the provider acquiesces with a decision that he or she knows to be medically inappropriate.[33] Thus, for example, if a Medicaid HMO were to order the premature and medically inappropriate discharge of a hospitalized patient, and the physician were to acquiesce without an appeal and sign the discharge papers, it would be the physician (perhaps ironically) who could be sued for malpractice if the patient suffers injury or death. From the law's perspective, the physician has the fiduciary medical relationship with the patient, and it is the physician who has broad powers over the patient's discharge.

LEGAL LIABILITY IN THE CONTEXT OF CARE FOR MEDICALLY UNDERSERVED POPULATIONS

Despite the apparent severity of these legal standards, the law is less harsh than would first appear. Courts have recognized that health professionals who understand the proper standard of care but, despite a fiduciary diligence on their part, are unable to meet it because of limited resources should not face liability.[33] In other words, the key to a defense in a professional liability action involving an indigent and vulnerable patient whose lack of proper care is the result of a larger systemic failure and a shortage of resources would be the ability to demonstrate—through detailed medical records and notes and the written description of conduct—recognition of the proper standard of care, as well as an active and energetic effort to secure the proper level of care for the patient. Such efforts might include arranging assistance with a Medicaid application, protesting the denial of coverage and actively helping in an appeal, intervening with hospital administrators in opposition to pressure to discharge indigent patients, and other actions that demonstrate a real effort to "do the right thing."

In the case of patient self-determination over matters such as continued medical care in the face of futility, the right to refuse medical treatment, and the right to health information privacy, the law treats low-income persons as it would any other patient population. Correspondingly, physicians who care for medically underserved populations operate under the same legal obligations relating to these rights as they apply to any other of their patients.[33] These obligations may raise additional challenges where language is a barrier. Physicians must ensure that their patients' medical records properly document not only their communications with patients but also their active effort to secure proper interpretation and translation services to ensure that communication is effective.

The law is so important to access and financing rights that some safety net providers have gone so far as to embed legal services into the range of care and services they offer. Other strategies might be the identification of community legal services programs and sources of pro bono legal assistance (a source of help in this regard may be local bar associations).

Where professional liability is concerned, health-care safety net providers, like health providers generally, are extensively engaged in risk management. The more energetic the effort on the part of safety net providers to assist patients to secure access to care, the stronger the evidence that their practice is consistent with rigorous standards of patient care quality.

CONCLUSION

There is no legal right to health care under US law, with the exception of those who are incarcerated (see Chapter 27). At the same time, there is a set of statutes that enable access in medical emergencies and prohibit certain forms of health care discrimination. US law also creates important rights in health-care financing. These rights are limited to certain defined categories of poor and medically indigent persons, and there is no federal law that creates coverage rights in all low-income persons. Health professionals should be familiar with the various statutory schemes not only because of their value to patients but also because active efforts to pursue patient rights may be essential to avoiding claims of legal liability.

- There is no legal right to health care in the United States.
- The federal government protects health through the court enforcement of laws and regulating programs supported by federal funding.
- Access to care issues, for example, are addressed through the following:
  - —EMTALA requires provision of screening and stabilization treatment to everyone who comes to the emergency department of a Medicare-participating hospital and requests care for an emergency medical condition.
  - —Title VI of the Civil Rights Act of 1964 prohibits racial and ethnic discrimination by health-care providers and institutions that are classified as recipients of federal financial assistance.
  - —HHS requires interpretive services for federally funded health-care institutions that treat patients with limited English proficiency.
  - —The ADA and Section 504 of the Rehabilitation Act prohibit discrimination against qualified individuals with disabilities and the ADA applies to health-care providers regardless of whether they accept federal funding.
  - —Medicaid, the major public health program that helps address access to care issues, provides important access, enrollment, and due process and bars discrimination in coverage based on health condition.
  - —Programs such as community health centers and the Ryan White Care Act, along with hospitals and public health clinics receiving state and local funding, have a legal duty to furnish health care to designated populations and communities.
  - —The ACA creates a new subsidized pathway to affordable private health insurance coverage for low- and moderate-income individuals and families who lack access to affordable employer coverage and who are ineligible for Medicaid or CHIP.

- State governments protect the health and welfare of their citizens by regulating the quality of care and license health-care providers.
- Courts determine the meaning of laws, enforce legal rights, provide remedies to individuals, and have substantive law-making powers under the principles of common law.
- Health professionals have no legal duty to provide care in most situations.
- Health-care providers owe their patients the accepted professional standard of care, even if that care is not covered.
- Health-care providers must make an active effort to obtain the appropriate level of care for their patients or are potentially liable for the poor care their patients receive.

Challenging Service Denials and Delayed Review Decisions

- Establish what the procedures are for the health-care system or payer whose service denial you wish to challenge.
- Follow an expedited review procedure if you believe that the denial or the delay in service could have rapid and harmful effects on your patient.
- Use health-care provider hotlines or other methods of direct contact when you are dealing with a delayed review decision.

Key Tips:

- Provide full, relevant clinical data to the agent denying the service.
- Explain the reasons why alternatives will not work for your patient. Be specific as to whether the proposed alternative solutions have been tried and failed or why they cannot be tried.
- Describe the health consequences of denying the service. Use medical literature and/or expert opinion to support your claim.
- Pay close attention to required forms and fill them out completely. Incomplete information can delay services for your patient.
- Ascertain if you are dealing with a delayed review decision.
- If your attempts to reverse a denial of service fail and you do not believe the alternatives are reasonable, assist your patient in appealing the denial by providing additional supporting information that might be needed for the appeal.
- Document your efforts to challenge a denial of service in patient's chart.
- Seek legal counsel and notify risk management at site of care.
- Refuse to execute orders flowing from a denial (e.g., discharging a patient after additional hospital days have been refused) that you do not believe are clinically indicated.

DISCUSSION QUESTIONS

1. What role should the courts play? In what ways might the courts protect you as you serve vulnerable populations? For what reasons might the courts restrict or punish you?
2. Should there be a general right to health care in the United States? Should there be a general legal duty to provide care? How do your answers to these questions conflict or complement each other?
3. What, if anything, should providers do, legally and ethically, to improve access to care for vulnerable populations?

RESOURCES

Kaiser Family Foundation (www.kff.org)

National Health Law Program (http://www.healthlaw.org)

United States Department of Health and Human Services (http://www.hhs.gov)

Urban Institute (http://www.urban.org)

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Chapter 5

Principles in the Ethical Care of Underserved Patients

Bernard Lo, MD and Robert V. Brody, MD

Objectives

- Identify the ethical dilemmas that commonly arise in the clinical care of medically underserved patients and populations.
- Review the ethical guidelines that should guide the physician's approach to such dilemmas and how to resolve them.
- Summarize what special responsibilities arise for physicians in the care of underserved patients.

INTRODUCTION

Eradicating the disparities in health and health care that exist between rich and poor is medicine's biggest ethical challenge the world over. Tackling this problem is an issue not only of medical ethics but social justice and raises questions about physician's social and political responsibilities. The obligation to work toward a more just society and system of health care is not universally acknowledged as a professional responsibility. For example, in the United States, there is no obligation for physicians to care for the underserved beyond stabilization in an emergency department or for prisoners. The health-care system and corporate interests are intertwined, with corporate prosperity often trumping patient benefit. Hospital policies, insurers, the government, as well as reigning societal attitudes toward illness and poverty increasingly influence relationships between practitioners and patients.

As health-care providers and other activists advocate for the societal changes that equity in health requires, they must also assure that the vulnerable patients actually cared for receive high-quality, ethical, and compassionate care. There may be host of complexities to navigate to assure this care. Underserved patients frequently are members of ethnic and cultural groups whose decision-making customs and values may differ from those of people from more privileged backgrounds who often dominate the health-care professions. In addition, underserved patients often have low health literacy and numeracy, less education, or significant behavioral health disorders. Thus, to participate actively in their medical decisions and care, they may need additional assistance to gain sufficient understanding of their medical situation. Mistrust of the health-care system may be a potent, but unacknowledged, force in decision making.

APPROACHING ETHICAL ISSUES

Ethical problems arise when it is difficult to act without compromising one ethical principle for another, or personal, professional, or societal moral standards are in conflict. There are three common types of ethical problems. One, sometimes termed ethical distress, occurs when the provider knows what the right course of action is but cannot act on it. This occurs frequently in the care of the underserved. For example, when lack of resources makes it difficult or impossible to pursue the right course of action, ethical distress is created. Ethical conflicts or

dilemmas occur, on the other hand, when a course of action fulfills some moral goods but compromises others. Ethical conflicts may arise when there are competing compelling needs. A final common type of ethical quandary, referred to as a problem in locus of authority, arises not over how to approach a particular issue but in who has the moral authority to make a decision. This can be a particularly thorny issue, for example, in important treatment decisions for those with limited mental capacity to understand the risks and benefits of treatments.

FUNDAMENTAL ETHICAL GUIDELINES

The discipline of ethics provides methods and guidelines to use when approaching a difficult problem. Systematically reviewing several ethical principles can help formulate a response to ethical problems. For example, considering three fundamental but frequently conflicting ethical guidelines of justice, respect for persons, and acting in the patient's best interests may help clarify the best response to ethical dilemmas (Box 5-1). Other approaches to ethical problems focus more on the integrity of the relationship between the provider and the patient or the consequences of a decision.

JUSTICE

The term "justice" is used in a general sense to mean fairness. John Rawls, one influential American philosopher, contends that the justness of a society should be determined by evaluating the position of its most vulnerable members. In addition, it is important to act consistently in cases that are similar in ethically relevant ways. Otherwise, decisions would be arbitrary, biased, and unfair. Justice forbids discrimination in health care based on race, religion, or gender and supports a moral right to health care, with access based on medical need rather than social or economic status.

Box 5-1 Ethical Principles for Approaching Ethical Decision Making

Justice
Acting in the patient's best interest:

- Beneficence
- Non-maleficence
  - Maintaining confidentiality
  - Avoiding deception

Acting with respect:

- Autonomy
- Informed consent

Integrity of Relationships: "Ethics of Caring"
Consequences of decisions

Strong philosophical arguments support the idea that all persons should have access to a decent level of health care regardless of ability to pay; however, even with the Affordable Care Act, this is an aspiration rather than established public policy in the United States. The United States does not recognize a legal right to health care except in the emergency department (see Chapter 4) and for prisoners (see Chapter 27). Clinicians face difficulties if patients with clear need for medical care cannot pay for medications, tests, hospitalizations, home care, or other services. In health-care settings, justice often refers to the allocation of health-care resources. Allocation decisions are unavoidable because resources are limited and could be spent on other social goods, such as education or affordable housing.

RESPECT FOR PERSONS

Treating patients with respect entails several ethical obligations. First, health-care providers must accept the medical decisions of persons who are informed and acting freely. Individuals place different values on health, medical care, and risk. Hence, competent, informed patients have the power to reject their clinicians' recommendations about care; otherwise, their integrity and liberty are violated. More broadly, patients should have the right to choose among feasible options and share decision making with health-care providers, because in most clinical settings different goals and approaches are possible, outcomes are uncertain, and an intervention may cause both benefits and harms.[1] Thus, allowing people to be active participants in decisions about their medical care respects their self-determination. In addition to respecting the decisions of autonomous patients, clinicians should take steps to promote patient autonomy, by disclosing information and helping patients deliberate.

A second meaning of respect pertains to patients whose decision-making capacity is impaired. Physicians should still treat them as persons with individual characteristics, preferences, and values. Decisions should follow their preferences and values, so far as they are known. In addition, all patients, whether autonomous or not, should be treated with compassion and dignity.

Respect also is related to other important ethical guidelines, such as avoiding misrepresentation, maintaining confidentiality, and keeping promises. Breaches of these other guidelines cause wrong or harm to patients and compromise their autonomy. Acting in the patient's best interest and avoiding harm are other aspects of respect.

INFORMED CONSENT

Informed consent involves more than obtaining the patient's signature on consent forms. Clinicians must

discuss with patients the nature of the proposed care, alternatives, risks and benefits of each, and likely consequences and obtain the patient's agreement to care.[2] Health-care providers need to educate patients, answer their questions, make recommendations, and help them deliberate. Patients can be overwhelmed with medical jargon, needlessly complicated explanations, or too much information all at once. Because underserved patients often have poor health literacy or may not speak English fluently, taking additional steps to help these patients make informed decisions (e.g., spending more time discussing unfamiliar medical terms and concepts and working with interpreters) is crucial and often ignored (see Chapters 15 and 31).

The doctrine of informed consent means that adult patients may make decisions that differ from what health-care providers recommend or what their families want them to do. Indeed, patients may refuse treatment that may save or prolong their lives, provided their decisions are informed and voluntary.

In many cultures, patients traditionally are not a grave diagnosis is believed to cause patients to suffer, whereas withholding information promotes serenity, security, and hope.[3] Being direct and explicit may be considered insensitive and cruel. Families and physicians may try to protect the patient by taking on decision-making responsibility.[4,5] Family members from such a cultural background may ask the provider not to tell the patient a serious diagnosis, or even to deceive the patient into believing that there is nothing seriously wrong. Patients should not be forced to receive information against their will, even in the name of promoting informed decisions. However, the crucial ethical issue is whether the individual patient wants to know his or her diagnosis, not what most people from that cultural heritage would want. Many individuals in these groups want to know their diagnosis and prognosis, even if they are terminally ill. Therefore, health-care providers should ask patients how they want decisions to be made, saying that their usual practice is to provide information and make decisions together with patients, while offering patients the option not to be told information or turn over decision making to someone else. Respecting the choices of the patient regarding the decision-making process is important (see Core Competency).

EMERGENCY CARE

Informed consent is not required when patients cannot give consent and delay of treatment would place life or health in peril. People are presumed to want such emergency care unless they have previously indicated otherwise.

INTERVENTIONS WITHOUT THERAPEUTIC BENEFIT

Autonomy does not entitle patients or their surrogates to insist on whatever care they want. Providers are not obligated to provide interventions that have no physiologic rationale or have already failed.[6,7] For example, cardiopulmonary resuscitation would be futile in a patient with progressive hypotension despite maximal therapy. However, clinicians should be wary of using the term "futile" in looser senses to justify unilateral decisions to forgo interventions when they believe that the probability of success is too low, no worthwhile goals can be achieved, the patient's quality of life is unacceptable, or the costs are too high. Such looser usages of the term are problematic because they may be inconsistent and mask inappropriate important value judgments.

MAINTAINING CONFIDENTIALITY

Confidentiality respects patients' autonomy and privacy, encourages them to seek treatment and discuss their problems candidly, and prevents discrimination. However, maintaining confidentiality is not an absolute rule. Confidentiality may be overridden in certain situations to prevent serious harm to third parties or the patient.[8] The law may require physicians to override confidentiality in order to protect third parties, for example, public health reporting of tuberculosis and syphilis. In other situations, medical providers have a legal duty to report victims of elder abuse, child abuse, and domestic violence. These exceptions to confidentiality are justified because the risk is serious and probable, there are no less restrictive measures to avert risk, the adverse effects of overriding confidentiality are minimized, and these adverse effects are deemed acceptable by society.[9]

The Health Insurance Portability and Accountability Act (HIPAA) health privacy regulations have heightened awareness of the importance of confidentiality. The HIPAA regulations are not meant to inhibit transmission of information needed for patient treatment. Disclosure of patient information to other health-care providers for the purposes of treatment without having the patient sign an authorization form is permissible except related to HIV, mental health conditions, and substance use.

AVOIDING DECEPTION

Health-care providers sometimes consider using lies or deception in order to protect the patient from bad news or obtain benefits for the patient. Lying refers to statements that the speaker knows are false and that are intended to mislead the listener. Deception, which is broader, may be defined as statements and actions that are intended to mislead the listener, whether or not they are literally

true.[9] For example, the health-care provider may tell a patient that she has a "small growth" so that she does not think she has cancer. Or the provider may complete and sign a form for a patient to get a bus pass, even though he does not meet the criteria for physical disability. Although deception under these circumstances may be motivated with a desire to help the patient, it is ethically problematic. Deception violates autonomy because the person who is deceived cannot make informed decisions if he or she receives misleading information. Furthermore, deception undermines social trust because people cannot trust that other statements by the speaker are truthful.[10] If clinicians are known to use deception in some situations to help patients, they also may use it in other situations for other purposes, for instance, to deceive patients as well as third parties. It is especially problematic for them to lie or intentionally deceive others because the relationship between health-care providers and patients and society depends on trust.

ACTING IN THE BEST INTERESTS OF PATIENTS

The guideline of beneficence requires clinicians to act for patients' benefit.[11] Lay people do not possess medical expertise and may be vulnerable because of their illness. They justifiably rely on medical providers to provide sound advice and promote their well-being. Medical professionals encourage such trust. Hence, clinicians have a fiduciary duty to act in the best interests of their patients. The interests of the patient should prevail over physicians, other providers, or third parties' (e.g., hospitals or insurers') interests. These fiduciary obligations contrast sharply with business relationships, which are characterized by "let the buyer beware," not by trust and reliance.

The guideline of "do no harm" forbids physicians from providing ineffective interventions or acting without due care.[12] Although often cited, this precept often provides only limited guidance, because many beneficial interventions may have serious risks. The challenge is to provide interventions whose benefits outweigh the risks and whose risks are acceptable; both of these determinations need to be made from the perspective of the patient.

UNWISE PATIENT DECISIONS

Patients' refusals of care may thwart their own goals or cause them serious harm. For example, a patient with shortness of breath caused by a severe asthma exacerbation may refuse treatment with bronchodilators and corticosteroids. Simple acceptance of such refusals, in the name of respecting patient autonomy, is ethically problematic. Acting in the patient's best interests requires eliciting patients' expectations and concerns, correcting misunderstandings, and trying to persuade them to accept highly beneficial therapies. If disagreements persist after discussions, the patient's informed choices and view of his or her best interests should prevail. Although refusing recommended, highly beneficial care does not render a patient incompetent, it may appropriately lead the physician to probe further to ensure that the patient is able to make informed decisions (see Chapter 44).

ETHICS OF CARING AND RELATIONSHIPS

Weighing the important ethical principles in a medical decision can be a detached, impersonal process. One ethical approach, known as the "ethics of caring," recognizes that ethical decisions are embedded in relationships. Grounding actions in caring rather than on principles that are more abstract requires integration of ethical principles and reasoning but goes beyond them. Impartiality should not be the primary goal of the provider–patient relationship. Rather, the goal of caring is maintaining a partiality that inspires receptivity to the patient's needs and willingness to take responsibility for the patient, while not showing unwarranted favoritism or arbitrariness. Caring for a patient emphasizes compassion more than fairness. Recognizing alienation as an important component of human suffering, it is an approach particularly relevant to the care of the underserved. Communication skills and self-reflection to identify what—from fatigue to prejudice—limits one's ability to care for patients are skills highlighted by this perspective and may help eliminate what at first blush are thought of as ethical issues, but are in fact failures in communication.[13]

HELPING PATIENTS GAIN ACCESS TO CARE

Even with the Affordable Care Act, health-care resources for underserved patients may be constrained; health-care providers may need to serve as advocates for their patients to help them get needed medical care (see Chapter 8). As advocates, providers intercede for or speak on behalf of their patients.[14] Advocacy should be based on sound clinical judgment and evidence. It is not doing whatever the patient requests or whatever the provider believes would be beneficial.

Advocating for a patient is fair only if it also would be appropriate for others to advocate for other patients in similar situations. For instance, patients may not be able to afford a prescribed medication, or they may be refused coverage for needed in-home services or physical therapy. Those who claim that their responsibility is only to order medically appropriate tests and treatments have a very restricted view of their professional responsibility. Indeed, patients receive little good if they face insurmountable barriers to obtaining ordered care. Thus, in addition to ordering tests and writing prescriptions, clinicians need to

understand the barriers to obtaining ordered care. Helping patients navigate systems to gain health-care coverage and advocating for systems of care that eradicate these barriers is important to assuring all patients receive ethical care.

Furthermore, patients may lack shelter or other necessities. The concept of beneficence should be interpreted broadly to include not only medical tests and treatments but also other goods, such as shelter, food, and clothing, the lack of which will adversely affect health. Referring patients to appropriate social service agencies and completing the administrative paperwork required to apply for social services or financial assistance is an important aspect of medical care.

LIMITS TO ACTING ON BEHALF OF THE PATIENT

The ethical obligation to act in the best interests of patients and be an advocate for them is not absolute or open ended.[15] Physicians cannot guarantee that they can obtain needed assistance for patients. Although often the point of contact for underserved patients with social institutions, it is unrealistic for clinicians to feel they are responsible for correcting all the injustices their patients encounter. Nor are they expected to use their personal resources to help patients fulfill their needs.[16] Acting in the patient's interests means providing additional time and effort to a patient's care if such effort will have an important benefit for the patient and will not have undue personal burdens on the physician. It does not mean that physicians must make unreasonable sacrifices in their personal lives to serve their patients. Indeed, it would be counterproductive to try to do so (see Chapter 45). Navigating the boundaries of the doctor–patient relationship requires a careful analysis of risks and benefits, must be contextual and caring rather than inflexible and arbitrary, and can present an opportunity to renew our professionalism and humanity.[17]

ETHICALLY PROBLEMATIC STRATEGIES INTENDED TO HELP PATIENTS

In addition to helping individual patients obtain needed care, health-care providers need to consider the larger social and political context that makes it difficult for patients to receive needed care.[18] To obtain benefits, such as disability, patients need providers to give information to third parties. Health-care providers may consider, or patients may request, using lying or deception to help them gain such benefits. In one survey, 39% of physicians reported that during the past year they had exaggerated the severity of a patient's condition, changed a patient's billing diagnosis, or reported signs and symptoms the patient did not have in order to help the patient get needed care.[19] Such deception is more common when physicians believe that it is unfair for an insurance plan not to cover the intervention, when they believe that the insurer's appeal process is unwieldy, and when the patient's condition is more serious.[20] However, avoiding deception is a basic ethical guideline that serves to limit obligations to serve as patient advocates.[21] Those dealing with a specific case may not appreciate the impact of the practice of deception on the doctor–patient relationship and on the role of health care in society.

Another approach to helping low-income patients is not to collect the copayment required by insurers. Forgoing the income from such copayments is ethically praiseworthy because it makes medical care more affordable to patients with limited means. However, in the United States, some insurers contend that if the physician is willing to accept a discounted rate for their services, then their usual fees are in fact lower than what they are charging the insurer and seek to lower the reimbursement rates or even accuse the physician of fraud. Thus, the physician or clinic that wishes to give a discount to patients in need is wise to seek legal counsel to make sure it is being done in a manner that avoids legal liability.

BEDSIDE RATIONING: CONFLICTING ETHICAL GUIDELINES

> Mrs. Diaz is a 76-year-old woman with severe dementia. She recognizes her family only occasionally and does not respond to questions or requests by health-care workers. She develops chronic renal failure and symptoms of uremia. While competent, she had never expressed her preferences regarding renal dialysis. Although her primary physician and the nephrologist strongly recommend that renal dialysis not be performed, her family insists on it; they believe that as long as she recognizes them and smiles, her life is meaningful and should be prolonged. They understand that dialysis would not improve her mental functioning or mobility.
>
> At the time, the public hospital in the community is considering closing obstetric and substance abuse services because of budget deficits. The physicians feel they are accomplices with an unjust health-care system if they use resources on this patient when more pressing health needs are unmet. A vascular surgery consultant writes in the medical record, "In the current climate of out-of-control medical costs, it is unconscionable to provide expensive care for this patient."[17]

In accordance with the guideline of beneficence, the family is acting as surrogate for a patient who lacks decision-making capacity. In this case, the family believes that dialysis is in Mrs. Diaz's best interests, according to their assessment of her quality of life. However, the physicians believe that Mrs. Diaz's quality of life is so poor that the cost of dialysis is not justified. They claim that the guideline of justice requires them to allocate resources fairly among the population as a whole and act as responsible

stewards of scarce medical resources. Physicians should support enlightened public policies about allocation. However, in most circumstances, attempts by physicians to redistribute health-care resources at the level of the individual patient, although well intentioned, generally are both unjustified and ineffective.

ARGUMENTS AGAINST BEDSIDE RATIONING

Traditionally, bedside rationing by physicians has been considered unethical.[22,23] At the bedside, physicians generally should act as patient advocates within constraints set by society, reasonable insurance coverage, and sound clinical practice. One eminent physician wrote, "Physicians are required to do everything that they believe may benefit each patient without regard to costs or other societal considerations. In caring for an individual patient, the physician must act solely as the patient's advocate, against the apparent interests of society as a whole."[24]

There are several strong ethical reasons against bedside rationing in the case of Mrs. Diaz.[25] First, no public policy authorizes physicians to carry out such rationing. The physicians caring for Mrs. Diaz felt partly responsible for the soaring cost of health care. However, no public policy authorizes physicians to limit the care of patients on renal dialysis to save resources for other patients. On the contrary, US public policy pays for dialysis to all patients with end-stage renal failure through the Medicare program. Second, bedside rationing would be inconsistent and unfair. Physicians at one hospital might withhold dialysis from Mrs. Diaz, whereas physicians at another hospital might provide it. Treating similar patients unequally violates the ethical guideline of justice. Whether Mrs. Diaz receives dialysis or not should not be based on the physician or hospital that provides her care, particularly, because underserved populations often have little choice of providers. Bedside rationing may also be unfair if certain patients or interventions are singled out for review. It makes little sense to limit one health-care intervention as not cost-effective without scrutinizing the cost-effectiveness of other interventions, such as intensive care for patients with extremely poor prognoses. Unfairness may also result from unilateral quality-of-life judgments made by physicians. Empiric studies show that physicians tend to rate a patient's quality of life lower than do patients or their families. This may be particularly true if patients and physicians come from different backgrounds. Physicians believed that Mrs. Diaz's quality of life fell below a threshold of acceptability. However, the family, who seem loving and well intentioned, believe that her life still has meaning and value. In the US culture, which prizes respect for the beliefs and values of individual patients or their surrogates, there is no societal warrant for physicians to impose their own evaluations of quality of life to override the family's assessment in this situation.

Third, money saved by rationing usually cannot be reallocated. Physicians in the United States who save money on the care of an individual patient generally cannot redirect those resources to patients or projects that have higher priority.[26] If physicians terminated dialysis on Mrs. Diaz, they could not redirect funds to more pressing medical or social needs, such as prenatal care or childhood immunizations. Attempts to limit health-care costs at the bedside are ineffective gestures that could lead to disparities in health care.

In several situations, bedside rationing can be justified. An example is when the intensive care unit (ICU) is full and a patient in the hospital develops a crisis that is unlikely to respond well without ICU care. In this situation, it would be appropriate to transfer a more stable patient with less urgent need of intensive care out of the unit to a general ward bed. When physicians are part of the leadership of care delivery organizations, participating in making rules and guidelines about resource allocation for systems that have resource constraints—either monetary or capacity (limited supplies of hospital beds, methadone treatment slots, nurses, personal protective equipment, etc.), they must distinguish between their role in setting guidelines and that of being a health-care provider. They must not make case-by-case bedside rationing decisions as individuals but rather play within the rules that they have helped establish as members of the system.

In situations where rationing is permissible, clinicians may be reluctant to ration interventions to patients who are already receiving care because of loyalty or fidelity. That is, physicians may believe that they have implicitly promised to provide ongoing care and not to curtail it to benefit other patients. The emotional appeal of this position is clear, and keeping promises is an important ethical guideline. However, maintaining fidelity should refer to appropriate ongoing care, not to unlimited care regardless of the benefits to the patient or the harm to others.

- Often more than one ethical guideline is at play in a case; these different guidelines may direct providers to act in opposite ways. There may be strong reasons both for and against a particular course of action.
- Stakeholders may have different values and approaches to decision making. Physicians, nurses, family members, and the patient may not agree on the risks and benefits of an intervention, the patient's quality of life, or the process of decision making.
- In determining the ethically appropriate course of action, providers need to articulate the reasoning that led them to their recommendation or position.

PATIENTS WHO LACK DECISION-MAKING CAPACITY

Patients may not be able to make informed decisions because of unconsciousness, dementia, delirium, or other medical conditions. The highly publicized case of Terri Schiavo, a young woman in a persistent vegetative state, illustrated how difficult and contentious decisions can be for such patients.[27,28] In this case, the husband and parents disagreed sharply over whether her feeding tube should be discontinued. In a lengthy legal process, the state and federal courts, the Florida state legislature, the Congress, and the president were involved in the case. In cases involving patients who lack decision-making capacity, physicians need to ask two questions: Who is the appropriate surrogate? What would the patient want?

ASSESSING CAPACITY TO MAKE MEDICAL DECISIONS

All adults are considered legally competent unless declared incompetent by a court. In practice, physicians usually determine that patients lack the capacity to make health-care decisions and arrange for surrogates to make them, without involving the courts. By definition, competent patients can express a choice and appreciate the medical situation, nature of the proposed care, and alternatives, as well as the risks, benefits, and consequences of each.[29] Their choices should be consistent with their values and not result from delusions or hallucinations. Decision-making capacity is task specific: some patients can make simple decisions about their care but are unable to understand the risks, benefits, or consequences of more complicated medical situations.

Patients who carry a diagnosis such as dementia, schizophrenia, or substance abuse should not be automatically considered to lack decision-making capacity. Although such diagnoses may raise the question of decision-making capacity, the physician needs to evaluate each patient as an individual.[29] Psychiatrists may help in evaluating difficult cases because they are skilled at interviewing mentally impaired patients and can identify treatable mental health conditions, but the physician primarily responsible for the patient's care retains the responsibility for deciding about this aspect of care as well. When impairments are fluctuating or reversible, decisions should be postponed if possible until the patient recovers decision-making capacity.

CHOICE OF SURROGATE

If a patient lacks decision-making capacity, physicians generally ask family members to serve as surrogates. This approach is appropriate because most patients want their family members to be surrogates, and family members generally know the patient's preferences and have the patient's best interests at heart. Patients may designate a particular individual to serve as proxy; such choices should be respected. Some states have established a prioritized list of which relative may serve as surrogate if the patient has not designated a proxy.

STANDARDS FOR SURROGATE DECISION MAKING

Guidelines have been developed to help physicians working with surrogates for incapacitated patients to ensure that the medical decisions made are as close as possible to those the patient would have made for himself or herself.

Advance Directives

These are statements by competent patients to direct care if they later lose decision-making capacity. They may indicate: (a) what interventions they would refuse or accept or (b) who should serve as surrogate. Following advance directives respects patients' autonomy.[30]

Physicians can encourage patients to provide advance directives, to indicate both what they would want and who should be surrogate. In addition, physicians should discuss with patients the scenarios that are likely to occur and the options for each. These discussions help ensure that advance directives are informed and up to date. Furthermore, doctors should encourage patients to discuss their preferences with their proxy. The federal Patient Self-Determination Act requires hospitals and health maintenance organizations to inform patients of their right under state law to make health-care decisions and to provide advance directives.

Substituted Judgment

In the absence of clear advance directives, surrogates and physicians should try to decide as the patient would under the circumstances, using all information that they know about the patient. Although such substituted judgments try to respect the patient's values, they may be speculative or inaccurate. Commonly, surrogates may decide based on their own values rather than the patient's, or they may be mistaken about the patient's preferences, particularly when they have not been discussed explicitly. A decision by a surrogate known to the physician to be contrary to a patient's wishes should not be implemented.

Best Interests

When the patient's preferences are unclear or unknown, decisions should be based on the patient's best interests. Patients generally take into account the quality of life as well as the duration of life when making decisions for themselves. It is understandable that surrogates would also consider quality of life of patients who lack decision-making capacity. Judgments about quality of life are appropriate if

they reflect the patient's own values. Bias or discrimination may occur, however, if others project their values onto the patient or weigh the perceived social worth of the patient.

Legal Issues

Physicians need to know pertinent state laws about patients who lack decision-making capacity.[31] A few state courts allow doctors to forgo life-sustaining interventions only if patients have provided written advance directives or very specific oral ones.

Cultural Issues

Advance directives are supported in the United States by court rulings, professional ethics, and common clinical practice. However, in many cultures, decisions for patients who lack decision-making capacity are made quite differently.[32] First, in many other cultures, the individual may be regarded as a member of an extended family unit. Thus, patients expect their children to take care of them and make appropriate decisions for them, and traditionally children expect to take responsibility for elderly family members who no longer can care for themselves. Second, advance care planning may seem strange and inappropriate in cultures where it is viewed as impolite and insensitive to talk explicitly about serious illness and death. Indeed traditionally, patients may not have been told of serious diagnoses, such as cancer, lest the news inflict needless suffering. Explicit advance care discussions and written advance directives may be regarded as unnecessary or mistrusting of family members. To name one person as decision maker also may seem inappropriate because it devalues the role of other family members and the importance of family consensus. Third, in some communities, religious beliefs form the basis of decisions regarding medical care; physicians need to respect patients' religious commitments, even if they differ from their own. Fourth, families from some cultural or ethnic backgrounds may mistrust the health-care system and believe that doctors discuss advance directives because they do not want to provide care that patients need. Such mistrust is understandable in light of the history of discrimination, segregation, and unequal access to medical care that, for example, African Americans have experienced in the United States.[33] Physicians need to understand such concerns and views. However, traditions and beliefs may change, and in many countries patients today are more likely than before to want to know the diagnosis and play an active role in their own care. Furthermore, families today may be more dispersed geographically than previously. Physicians should never assume that a patient holds beliefs about end-of-life care that are traditional in their culture but instead treat each patient as an individual.

Open-ended questions can elicit the patient and family's preferences for decision making and their concerns and values. Physicians need to spend sufficient time listening attentively to understand the patient and family's perspective.[34] If patients and families feel that the physician understands them, they are likely to be more willing, in turn, to listen to the physician's recommendations. It is helpful to ask specifically about lack of trust in the medical system and to acknowledge that this is an understandable reaction.

Disagreements

Disagreements may occur among potential surrogates or between the physician and surrogate. Physicians can remind everyone to base decisions on what the patient would want, not what they would want for themselves. Including the family's religious or spiritual advisor and consultation with the hospital ethics committee or another physician often helps resolve disputes.[35,36] Such consultation is also helpful when a patient has no surrogate and no advance directive. Some communities and institutions have developed protocols to make decisions for "unbefriended" patients. The courts should be used only as a last resort when disagreements cannot be resolved in the clinical setting.

HASTENING DEATH

As of this writing, five US states, by voter initiative, legislative action, or judicial decision, have legal protections for physicians who provide terminally ill adults with the means to hasten their death. No physician is required to write a lethal prescription. For those physicians who see this action as a profound demonstration of respect for patients, it is incumbent on them to follow the safeguards included in the various laws, or the best practices that have evolved, to protect vulnerable patients. These include verifying and documenting that a patient has a terminal illness, decision-making capacity, the absence of a mental disorder clouding decision making, the absence of familial or social pressure to hasten death, and a consistent wish to hasten death even in the context of high-quality care.[37]

ETHICAL CONSULTATION

Accrediting agencies in the United States requires participating hospitals to have some mechanism for assisting providers in resolving ethical dilemmas which arise in care; most larger institutions fulfill this obligation with a multidisciplinary ethics committee, including members from the community served by the institution. Members knowledgeable in ethics make themselves available to colleagues to answer questions about pertinent laws or institutional policies or to participate in a case conference to sort through more complicated issues, such as patient decision-making capacity or surrogacy, withholding or withdrawal of specific treatments, transition to comfort

care, difficult dispositions, dealing with cultural aspects of care, or coping with behavioral issues. In rural areas, ethic networks may consult virtually to provide support to isolated practitioners. An ethics case conference ideally includes those providers from across the spectrum of care, including outpatient providers, who have the most experience with the patient and his or her values, as well as current providers. The patient and/or surrogate may or may not be present. After a presentation of the updated clinical situation, including pertinent medical, psychological, and social information, there is a statement of the issues with ethical implications to be addressed in the consultation, followed by a discussion of each issue and consideration of ethical principles and conflicts which have arisen in the patient's care. Often, rather than making specific recommendations, an attempt is made to facilitate a consensus among those present about the best path forward.

CONCLUSION

Ethical dilemmas are inevitable in clinical medicine because individual health-care workers, patients, and families have different preferences and priorities. Patients, family members, and other health-care workers may have religious or cultural backgrounds different from the physician. Furthermore, health care and other societal resources for underserved populations do not meet their clinical needs.

Clinical ethics can indicate which actions are clearly right or wrong and which are controversial. Some positions on specific ethical issues can be shown to be untenable because they are internally inconsistent or do not take into account countervailing arguments. In other situations, people can be persuaded to reach agreement in a particular case, even though they hold different world views.

Although analysis of ethical issues is essential, few dilemmas in clinical ethics are resolved solely by philosophical arguments. Good communication and interpersonal skills are also needed. Physicians need to identify and address common factors such as emotions, misunderstandings, interpersonal conflicts, and time pressures that often complicate clinical dilemmas. Indeed, many "ethical" dilemmas are settled by addressing these issues directly through showing respect for others, concern, and compassion.

Physicians confronting ethical dilemmas can get help from other members of the health-care team, colleagues, or an institutional resource (an ethics committee or consultant). Such discussions, which will try to invite all involved providers, inpatient and outpatient, often can clarify the ethical issues and suggest ways to improve communication and deal with strong emotions. When struggling with difficult ethical issues, physicians may need to reevaluate their basic convictions, tolerate uncertainty, and maintain their integrity while respecting the opinions of others.

- In the care of any patient, ethical dilemmas may arise.
  - Patients may disagree with providers' recommendations.
  - People may disagree over how to weigh the benefits and risks of an intervention.
  - The well-being of the individual patient may conflict with the well-being of other persons.
- In caring for underserved patients, providers have additional responsibilities to:
  - Overcome barriers to informed consent.
  - Obtain access to care and social services.
  - Understand and respond to the cultural framework of the patient.
  - Advocate for change in public policies that contribute to health disparities.
- Physician responsibilities to underserved patients are not absolute or unlimited. Advocacy needs to be balanced with physician well-being.

Responding to Family Requests Not to Tell the Patient the Diagnosis of Cancer

A 70-year-old Cantonese-speaking man is found to have a carcinoma of the lung. His children ask the physician not to tell their father he has cancer. They say that if he is told, he will lose hope. (This situation can occur with patients from any cultural background.)

- Determine what the patient wants. Individual patients may wish to know they have cancer, even if this is not customary in their culture. This conversation is best done before embarking on a diagnosis and confirmed before delivering results.
  - ASK patients for THEIR preferences
    Example: "Many patients want to know their test results, whereas other patients want the doctor to tell a family member. I will do whatever you prefer. Do you want me to tell you the test results?"
  - Respect the patient's preferences.
- Elicit the family's concerns.
  - Ask about fears
    Example: "What do you fear most about telling your father he has cancer?"
  - Validate feelings as the natural reactions of loving relatives
  - Explore steps to be taken to address concerns and to help family and patient cope.
  - Offer compassion and empathy, and help mobilize support for family and patient.

- Plan for future contingencies if withholding information. If the diagnosis is withheld, physicians need to anticipate future issues that might arise.
  - Ask regularly if patients have questions or want to discuss anything else about their condition. Patients who do not want to be told their diagnosis may change their minds.
  - Do not promise family members that the patient will not learn a serious diagnosis. (It may be disclosed inadvertently.)
  - Communicate patient's desires to other health-care team members.

DISCUSSION QUESTIONS

1. A 34-year-old primary school teacher is diagnosed with active tuberculosis. The patient is afraid that she will lose her job if her case is reported. She will start treatment immediately and notes that summer vacation has just started. She is willing to come to the office to take her medicine or take tests to prove she is taking her drugs.

   Should she be reported to public health officials?
   What ethical considerations support your position?

2. A 62-year-old woman is diagnosed with localized stage I breast cancer, which usually can be cured with lumpectomy plus radiation or mastectomy. The patient does not speak English, and her daughters request that you not tell her she has cancer. "In her generation, people aren't told they have cancer. She would just give up hope. It would be disrespectful to make her suffer, rather than have the family bear the burden of her illness. Just tell her she needs an operation, and she'll agree to it."

   Do you agree to the daughters' request?
   Give the ethical considerations for your decision.

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Chapter 6

Community Engagement and Partnership

Naomi Wortis, MD and Ellen Beck, MD

Objectives

- Describe how health professionals may promote health equity through community engagement.
- Discuss the importance of partnering with the community.
- Outline how a health professional can engage with a community, including the Community-Oriented Primary Care (COPC) model.
- Discuss how to define a target community.
- Describe techniques of healthy community assessment.
- Explain how health professionals can promote community empowerment.

Health depends, in large part, on the social context within which a person lives. Community, a concept derived from the Latin word communitas, meaning common or shared,[1] will be defined in this chapter as a group of people with a shared identity. The community or communities with which an individual identifies define their social context and are potent determinants of health (see Chapter 1).

Engaging with communities to address the broader social and environmental conditions that undermine health is an important role for health professionals. The Centers for Disease Control (CDC) (http://www.cdc.gov/phppo/pce/) defines community engagement as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people."[2] Community engagement is a powerful tool for the promotion of health and health equity.

By partnering with a community, learning about its needs and resources, and assisting a community with community-based health interventions, health professionals have the potential to improve the well-being of many more people than they care for individually in clinical settings. For example, health professionals participating in addressing issues like eliminating "food deserts" in low-income communities, or contributing to community-based efforts to prevent violence, can contribute greatly to these endeavors. Ultimately, these efforts improve the health of their patients. One approach is through advocacy work, publicizing and campaigning for policy and political changes to reduce inequities (see Chapter 8). Another approach is to directly engage with members of underserved communities and community-based organizations and partner with them to implement programs at the local level.

This chapter discusses concepts and strategies for health professionals seeking to engage with communities at home and abroad, focusing particularly on community partnership and community assessment. Woven through this chapter is the story of the establishment of the San Diego, California–based Environmental Health Coalition (www.environmentalhealth.org) and its community health worker (or promotora) program.

PARTNERING WITH COMMUNITIES

The Environmental Health Coalition (EHC), a grassroots community organization, was founded in San Diego in 1980. It initially worked with union members concerned about occupational health and safety issues and community members concerned about cancer and other environmental illnesses. Founders included industrial workers, environmentalists, health and human service providers, and university professors. Their mission statement includes: "We believe that justice is accomplished by empowered communities acting together to make social change."[3] Health professionals from several southern California universities, including the University of California, San Diego (UCSD), have been involved in many of the projects undertaken by EHC.

The notion of partnership is fundamental to community engagement. Community health interventions by health professionals, whether domestic or international, are much more likely to be effective if they are done in partnership with that community. A community-based project is likely to be more successful than a community-placed project. A community-placed project is one in which an outside "expert" assumes she or he knows what a community needs, develops an intervention without community input, and then implements it. This can lead to (a) a project that is not valued by the community because it is not addressing one of the community's priorities; (b) methods that are culturally inappropriate; (c) duplication of interventions that have already been tried; and (d) a project that is not sustainable beyond the expert's involvement because it does not have community support. A true community-based project is one that grows from within a community and is led by community members. Community members identify needs and resources, implement an intervention, and sustain the project. Outside experts can participate in this process through effective partnering.

Box 6-1 lists important tasks for health professionals embarking on community engagement. We discuss these tasks in more detail in the following sections.

Box 6-1. Important Tasks When Embarking on Community Engagement

- **Assess** your own resources as a health professional and your short- and long-term interest in becoming partners with the community.
- **Engage** the community by identifying the relevant social networks and leaders and beginning to build relationships.
- **Prioritize** health problems using consensus-building techniques.
- **Develop** strategies to enlist community involvement in the intervention.
- **Evaluate** outcomes, involving the community from the start.

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COMMUNITY-ORIENTED PRIMARY CARE MODEL

There are many models for community-engaged work. One well-established framework is Community-Oriented Primary Care (COPC), a process through which health issues of a defined population are systematically identified and addressed.[4] Figure 6-1A shows a diagram of the COPC process. The first step is identifying and characterizing a target community. The second step is assessing the needs and resources of that community. The third step is designing and implementing an intervention to address a prioritized need. The fourth step is evaluating the success of the intervention. Involving the community at all stages is an integral part of the COPC model. Community members must be involved as partners, not merely as a source of data. Examples of this partnership include community members who help to define the target community, pose research questions, design survey instruments, gather and/or analyze data, prioritize health issues, design and/or staff interventions, perform evaluations, and write up results. It is ideal if community members have already initiated a community development process along the lines of COPC, and they invite the health professional to join them.

The COPC model is not unlike the process health professionals go through in caring for individual patients. See Figure 6-1B for a diagram of the patient care process. Patient care cannot be successful unless the health professional collaborates with the patient at each step. Patients are not only expected to provide information about their health problems. They are also expected to participate in treatment decisions, changing health behaviors, and monitoring their progress. Similar to engagement at the community level, it is ideal at the individual level if patients are taking the initiative to improve their health and involve a health professional to assist them.

Closely related to COPC is the community-based participatory research (CBPR) model.[5,6] True CBPR is research that embodies core principles of COPC, including community assessment and community engagement.

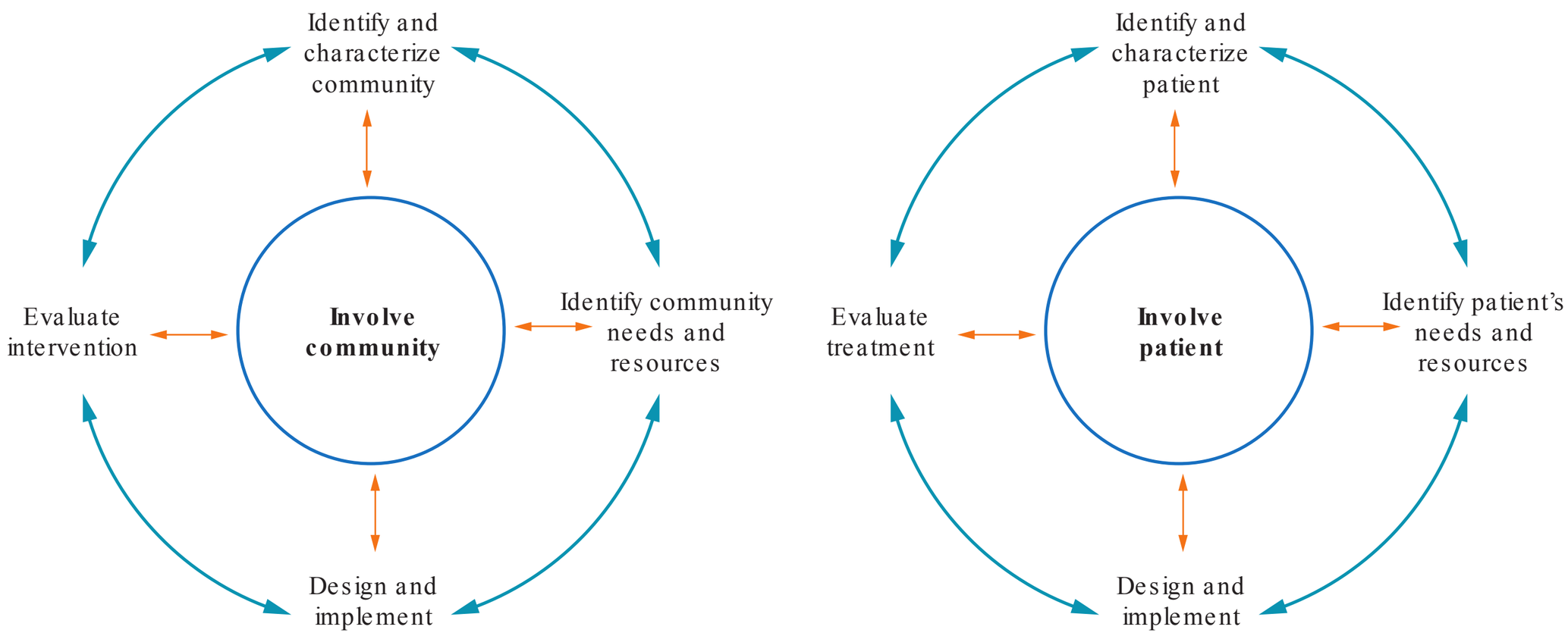


Figure 6-1. Comparison of community-oriented primary care (COPC) and patient care models. **A.** COPC process. (Adapted with permission from Rhyne R, et al. Community-Oriented Primary Care: Health Care for the 21st Century. Washington, DC: American Public Health Association, 1998.) **B.** Patient care process.

OVERCOMING THE CULTURAL DIVIDE AND DEVELOPING TRUST

SELF-AWARENESS

Awareness of the cultural divide that often exists between health professionals and underserved communities, and approaching community partnerships with humility, are foundational competencies for successful community engagement. Like all human beings, health professionals have their own biases and cultural norms, and effective community engagement, like effective patient engagement, requires self-awareness. Many health professionals are not members of the communities they serve. This is especially likely to be true for health professionals serving vulnerable populations at home or abroad. Not being a member of the community often means that health professionals face a cultural divide. This divide may include race, ethnicity, language, socioeconomic status, or belief systems, to name a few possible differences. These differences are magnified when working in a foreign country. Just as health professionals strive for cultural competence when delivering health care to individuals, they must work on learning about the realities of community life if they want to engage successfully with a community. Tervalon and Murray-Garcia suggested the term "cultural humility" rather than cultural competence.[7] They described cultural humility as incorporating "a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient–physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities."

ACADEMIC AND COMMUNITY PERSPECTIVE

The cultural divide commonly includes the gap between the academic medical perspective and the community perspective.[8] Freeman describes the academic perspective as more focused on theory, analysis, and educational value, and the community perspective as more focused on practical solutions, service, and action. Because of their different perspectives, academics sometimes behave in ways that are or appear to be disrespectful and generate mistrust in the community. For example, academics performing research in a community may promise to share results with that community; however, the communication of results may never happen. This missed step can represent a betrayal of trust from the community's perspective. Explaining what to expect of an academic approach and integrating elements of a community perspective may improve academic–community partnerships.

Trust tends to develop over time with long-term relationships, but health professionals often come into a community for a relatively short period defined by the duration of a course or a grant-funded project. Repeated experiences like this can leave community members feeling used and mistrustful of other health professionals who try to engage with them. Needs assessments that identify pressing social issues but do not lead directly to a subsequent intervention can be frustrating for community members.

COMMUNITY AND PROFESSIONAL EXPERTISE

Another potential element of the cultural divide between health professional and community is the paternalistic role that health professionals have often played with their patients—a role that may be extended into community work, with poor results. When doing international work, this can be reminiscent of the damaging effects of colonialism. When health professionals assume that they know what would be best for the health of their target community, they may alienate and disempower community members. Conversely, taking a more collaborative approach and heeding the collective wisdom within the community is more likely to build trust and promote community empowerment. Community members know their communities best and usually have considerable wisdom and practical perspectives about solutions to community problems. Both locally and globally, health professionals engaging with community members can ask for them and their communities to recommend solutions. Health professionals should listen when solutions are offered, sincerely consider these possible solutions, and respectfully offer or add their own expertise as health professionals to help the project succeed. This can lead to increased trust as well as increased likelihood of success, as the combination of community expertise and professional expertise often yields the best intervention strategies.

ENGAGING THE COMMUNITY

> Barrio Logan is a San Diego neighborhood with a mix of residences and industry, nestled between Interstate 5 and San Diego Bay's shipyards, 20 miles from the border with Mexico. Most of the residents of San Diego's Barrio Logan neighborhood are Latino, and 33% of families are living in poverty. There are strong community associations, ranging from labor unions to informal social networks of women.

Engaging the community involves two initial steps: defining the community, and gaining entry into the community and developing partnership.

DEFINING A TARGET COMMUNITY

There are several ways to define a targeted community: (a) a geographically defined neighborhood; (b) a group of people working or going to school together; (c) a group of people with some shared sociologic characteristic such as age, language, and a shared history, cause, or identity; or (d) a clinically defined population, such as persons with a particular health problem or patients served by a particular clinic.

The last definition of target communities has limitations. People with a particular health problem or patients of a particular clinic may not feel a shared identity with others in those respective groups, and shared identity is at the heart of any definition of community. The less a community has a sense of group identity, the harder it is to engage with that community in a way that encourages community members to take responsibility for improving overall community well-being. Moreover, if a health professional limits the target community to people with a particular health problem or patients of a particular practice, the health professional may miss the opportunity to reach out to people who have not yet been diagnosed with that problem or who have not yet accessed clinical care. Many opportunities for preventing disease also are missed. This significantly decreases the potential community health and health equity impact of any intervention that is undertaken.

Involving community members in the definition of the target community enhances the likelihood that the target community will have a shared identity and encourages community members to take responsibility for improving overall community well-being. In addition, there are advantages to defining a target community in a way that respects precedents for delineating the relevant population, particularly when those definitions align with existing categories for organizing and reporting population-level data. For example, a geographic community defined along census track lines allows census data to be used more easily. On the other hand, by defining a target community in a way that has been done previously, one has to be careful not to adopt imposed geographic boundaries or demographic group definitions that may not reflect the true degree of social connection and shared identity among the target population.

DEVELOPING TRUSTING PARTNERSHIPS

Once a target community is defined, health professionals must start to build relationships with collaborators in that community. Health professionals without existing relationships in a community must identify potential collaborators to approach, often beginning with key informants who are respected in the community and who may suggest other individuals and groups to approach. Building partnerships with preexisting community-based organizations or official community leaders is valuable; however, it is also essential to make sure that "grassroots" community members are consulted and involved in the project. True community leaders often exist outside of organizations. When that is the case, the health professional will find it difficult to gain the trust of the general community if she or he collaborates only with the governmental leaders. Also, it is important not to rely too much on any one community group or organization. The project can be undermined if that organization loses funding or

leadership, or if internal community politics do not favor the group. On the other hand, some projects bog down because they try to involve too many organizations from the beginning. Sometimes, the best approach is to develop a strong relationship with one organization, demonstrate to the community the value of the partnership, and then add other partners over time as trust is built.

To earn trust when approaching a community for a time-limited engagement, it is important to find out about the community's experiences and current expectations, to be clear and honest about time and programmatic limitations, to plan for mutual benefit, and to be realistic to deliver on promises made. It is helpful to partner with an existing community-based organization that already has and will continue a long-term relationship with the community. The time-limited nature of a grant or project should be discussed with partners in the planning and implementation and careful consideration should be given to sustainability of interventions.

The time of community members must be valued. When health professionals attend meetings for community projects, they often are doing this as part of their paid jobs. Community team members should not be expected to volunteer their time if other team members are not. If community members are expected to attend regular meetings, there should be consideration of reimbursing them for their time or offering another appropriate incentive, such as a grocery store gift card. Childcare and transportation might be provided to facilitate community participation.

Reflection, a key component of the service-learning educational model,[9] should be integrated into the process. Pausing to reflect as a team at each step of a project can strengthen partnerships by improving communication, promoting understanding, and preventing future problems. Reflection can be done verbally and/or in writing. Building on the reflection process, health professionals can help foster an environment in which all partners can share feedback honestly. Community members must feel comfortable sharing their feedback, and health professionals must listen carefully and respond respectfully to that feedback.

Learning how to partner with a community in order to undertake community health interventions is challenging. It takes patience and perseverance to do partnership work well, but the rewards can be tremendous. An international organization, Community-Campus Partnerships for Health, has identified twelve "Principles of Partnership," through an inclusive process involving community and academic partners (see Box 6-2).[10] These may be useful as guidelines for establishing new partnerships or as a checklist to assess existing partnerships. Highlights of these principles include respect, trust, clear communication, and shared power.

Box 6-2. Guiding Principles of an Authentic Partnership

1. Forms to serve a specific purpose and may take on new goals over time.
2. Agrees upon mission, values, goals, measurable outcomes, and processes for accountability.
3. The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment.
4. Builds upon identified strengths and assets, and also works to address needs and increase capacity of all partners.
5. Balances power among partners and enables resources among partners to be shared.
6. Partners make clear and open communication an ongoing priority in the partnership by striving to understand each other's needs and self-interests, and developing a common language.
7. Principles and processes for the partnership are established with the input and agreement of all partners, especially for decision making and conflict resolution.
8. There is feedback among all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes.
9. Partners share the benefits of the partnership's accomplishments.
10. Partnerships can dissolve, and when they do, need to plan a process for closure.
11. Partnerships consider the nature of the environment within which they exist as a principle of their design, evaluation, and sustainability.
12. The partnership values multiple kinds of knowledge and life experiences.

From CCPH Board of Directors. Position Statement on Authentic Partnerships. Community-Campus Partnerships for Health, 2013. Available at https://ccph.memberclicks.net/principles-of-partnership.

- Failing to define the target community clearly or appropriately
- Insensitivity caused by lack of awareness of the cultural divide between health professionals and community, often resulting in lack of trust
- Failing to learn about or assess the community
- Focusing only on community needs while overlooking community resources and community-generated solutions
- Failing to partner with the community, or failing to do so effectively

ASSESSING A COMMUNITY: MAKING PRIORITIES AND SETTING GOALS

> Pollution and poverty in Bario Logan adversely affect the environment and the community's health. In 1997, a team of community members, EHC staff, and health professionals conducted a health survey that revealed that approximately 20% of Barrio Logan's children were having severe asthma-type symptoms. EHC started working with a group of promotoras (community health workers), local women who are knowledgeable about and trusted by their community. Partnering with EHC, health professionals have provided technical training for the promotoras about a variety of health and environmental issues such as asthma and lead poisoning, increasing the promotoras' health literacy and building their capacity to promote health equity.

Successful community engagement and community health improvement programs require assessment of the community, including describing what resources already exist in the community and what needs are unmet. If this step is skipped or done superficially, the health professional may proceed with incorrect assumptions that can result in inappropriate health interventions, duplication of services, or interventions that are not sustainable. For example, there is often a temptation to start a brand-new program from scratch. It is often better for long-term community development to build on existing community assets than to start completely new programs.

NEEDS-FOCUSED AND CAPACITY-FOCUSED ASSESSMENT

In the book, Building Communities from the Inside Out, Kretzmann and McKnight describe two paths to community development: needs-focused and capacity-focused.[11] The traditional needs-focused path focuses solely on problems and needs, rather than including resources and possible solutions. This may have negative results at the community level, including fragmentation of services, funds being directed more to service providers rather than community members, community leaders highlighting problems rather than promoting strengths, outside experts being promoted as the only ones who can solve problems, focus on survival rather than development, and general community hopelessness.

Kretzmann and McKnight promote a resource-centered approach. They highlight identifying and connecting the building blocks of people and institutions as the keys to community development. Examples of these community assets include teens and elders; religious organizations and neighborhood groups; and local businesses, schools, and clinics. When community members identify and interconnect these assets, invest some of their own resources into the process, and take responsibility for setting priorities and finding solutions to fill gaps, the result is likely to be personal empowerment and successful community development.

HEALTHY COMMUNITY ASSESSMENT

Hancock and Minkler promote the idea of a "healthy community assessment" rather than the more traditional "community health assessment."[12] They build on Hancock and Duhl's definition of a healthy community, developed for the World Health Organization (WHO): "A healthy [community] is one that is continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other in performing all the functions of life and in developing to their maximum potential."[13] The healthy community assessment is thus a much broader assessment than a review of statistics on demographics, morbidity, mortality, and so on. Ideally, this assessment involves the community as active partners in performing the assessment.

A number of methods can be used to perform a healthy community assessment, and they can be grouped in different ways: primary data versus secondary data, studies versus stories, quantitative versus qualitative, and so on. These methods do not need to be mutually exclusive. In fact, mixed-method approaches, using primary and secondary data, and qualitative and quantitative approaches are ideal. Assessment methods may also be categorized based on the degree of contact with the community[12,14] (see "Core Competency").

No Contact Methods

"No-contact methods" consist of gathering official statistics and preexisting documents, often referred to as secondary data. These are good places to find out about demographics, health access, morbidity, and mortality. An enormous amount of data about many communities can be found online.

Minimal Contact Methods

Geographically defined communities can be assessed through a driving ("windshield") or walking tour. Health professionals might look for health clinics, hospitals, dental clinics, nursing homes, sources of mental health care, and pharmacies. It is also important to observe the people, houses, places of worship, community-based organizations, businesses, schools, parks, potential environmental hazards, police and fire services, and public transport.

Interactive Contact Methods

"Interactive contact methods" hold the potential for community empowerment through opportunities for community

members to be involved and acquire new skills and knowledge. These methods of community assessment can provide valuable primary data but require significant investments of time. Conducting surveys, focus groups, and key informant interviews of community leaders or representative samples of community members are examples of these methods. Conducting focus groups[15-17] and surveys[18,19] is complex, and is beyond the scope of this chapter, but there are many other sources of information on these subjects.

Key informant interviews are a mainstay of interactive contact methods. The first step is determining whom to interview. Anyone who is a member of a community or who works with a community can harbor valuable information about that community and be a key informant. They may be official leaders such as a member of a community advisory board, a local politician, a religious leader, a clinic director, a teacher, the executive director of a community-based organization, a nurse, a community health worker, or a business owner.

Informal "community leaders" are less readily identifiable to an outsider but are often invaluable sources of information and important allies. Informal community leaders are more likely than official leaders to live in the neighborhood, send their children to local schools, share the same socioeconomic status as the rest of the community, be sought out for advice by other community members, and be trusted by the community.

Interviews are particularly useful for learning about the history of the community, the positive aspects about the community, what resources exist, how existing services are perceived, what environmental hazards exist, and what needs are perceived. Key informants, like all people, come with their own biases. It is important to establish the nature and length of their association with the community. The greater number of key informants interviewed, the more well-rounded a view of the community is obtained.

A healthy community assessment is a necessary step for health professionals to take during the community engagement process. The depth of the assessment depends on the time and resources available. It is advisable to use multiple methods to get the fullest possible picture of the community.

INTERVENTION AND EVALUATION

After engaging with a community and learning about its needs and resources via a healthy community assessment, next steps are jointly establishing priorities and goals, developing interventions to achieve those goals, and evaluating processes and outcomes of the interventions. These steps must be taken with full community participation, and building on existing community resources. Combining effective process strategies with scientific evidence and community wisdom about what works and will make an intervention feasible and sustainable can lead to successes worth celebrating. Many different frameworks and methods exist to guide these steps. From aid in setting priorities (http://www.naccho.org/topics/infrastructure/accreditation/upload/Prioritization-Summaries-and-Examples-2.pdf) to developing and evaluating projects (http://ctb.ku.edu/en and http://www.naccho.org/topics/infrastructure/mapp/framework/clearinghouse/evaluation.cfm), extensive tools for these steps are widely available (see "Resources").

COMMUNITY EMPOWERMENT

> EHC promotoras advocated at San Diego Port Commission meetings and were ultimately successful in stopping methyl bromide fumigations at a fruit warehouse just a quarter mile from the Barrio Logan elementary school and local homes. Community members participated in rallies, press conferences, candlelight vigils, visits to local politicians, and signing of petitions to achieve their victory. Local artists have woven some of EHC's work into beautiful and powerful community murals as a form of social advocacy.

For a community to become healthier, community members need to lead the process. Health professionals who are partnering with a community on health projects should promote this and not inadvertently undermine it. This is analogous to the way in which health professionals must facilitate patients' taking charge of their own health. Just as the principles of person-centered care are especially important with vulnerable patients, the parallel approach to community work is especially important with vulnerable and underserved communities. It supports those communities in becoming stronger, healthier, and more empowered.

McKnight suggests the following values for health professionals working with communities[20]: (a) respect community wisdom, (b) share health expertise in the form of understandable information that enables the community to solve its own problems, (c) promote the use of system resources for the enhancement of community capacities, and (d) focus on magnifying the gifts, capacities, and assets of individual community members and the community as a whole. In these ways, health professionals can promote empowered communities.

CONCLUSION

Fostering healthy communities and partnering with communities are important roles for health professionals. It takes time, patience, and perseverance to build trust and to make partnership work well. Through community engagement, community assessment, and community partnership, health professionals can expand their reach

beyond those individuals who enter the doors of their clinic and promote health equity through broader community improvement. Using these approaches, health professionals have the opportunity to improve the lives of individuals and the communities in which they live and work.

- Engage with the community in some way.
- Use the Community-Oriented Primary Care (COPC) model, involving community members.
- Conduct broad healthy community assessment using multiple methods.
- Build partnerships with community members in all phases of work to produce a community-based project.
- Evaluate your interventions.
- Promote community empowerment whenever possible.
- Understand that partnerships take time to build and develop.

Methods for Healthy Community Assessment

1. **No Contact Methods (useful preliminary step)**
   a. Review official statistics (e.g., census data, public health department data, school district data, birth/death records, crime rates)
   b. Review documents (e.g., community newspapers, newsletters, progress reports, bulletin boards)
   c. Review websites
2. **Minimal Contact Observational Methods**
   a. Driving or walking tour
   b. Visits to neighborhood businesses (e.g., a coffee shop, a store, or a nursing home)
   c. Attendance at community meetings (e.g., attend a PTA meeting or a religious service)
3. **Interactive Contact Methods**
   a. Key informant interviews
   b. Small group methods (e.g., focus groups)
   c. Surveys (e.g., door-to-door or other face-to-face interviews)
4. **Participatory Methods**
   Any of the listed methods when done in partnership with community members

Adapted from Hancock T, Minkler M. Community health assessment or healthy community assessment: Whose community? Whose health? Whose assessment? In: Minkler M, ed. Community Organizing & Community Building for Health and Welfare, 3rd ed. New Brunswick, NJ: Rutgers University Press, 2012;153–170.

DISCUSSION QUESTIONS

Identify a community with which you would like to work.

1. How would you define that community? What are the advantages and disadvantages of defining the community in this way? Would the community you are defining recognize themselves as a community and/or define community in the same way?
2. At what point in your work with the community would you begin to involve community partners? Why? With whom might you partner? How would you identify and/or decide with whom you will partner?
3. What will be some of the challenges to developing effective community partnerships? How will you overcome those challenges?
4. How will you learn more about the community? What kinds of information are you looking for? What are the best methods of getting the information you need?
5. Give some examples of community-based health interventions that you and your partners might consider implementing in this community. Is there evidence for your intervention? For each example, think of what might be the challenges to implement this model and how would you address the challenges. What would be your first step?

RESOURCES

www.ccph.info

Community Campus Partnerships for Health (CCPH): A nonprofit organization that promotes health through partnerships between communities and higher educational institutions.

http://ctb.ku.edu/en/toolkits

Community Tool Box: Maintained by the University of Kansas, this Web site provides over 7,000 pages of practical guidance on over 300 different topics related to community building.

www.environmentalhealth.org

Environmental Health Coalition: A grassroots organization dedicated to achieving environmental and social justice.

http://naccho.org/toolbox/

National Association of City and County Health Officials has many tools, courses, rubrics available outlining approaches to community engagement

http://www.thecommunityguide.org/index.html

Guide to Community Preventive Services

http://www.rwjf.org/en/how-we-work/rel/tools-and-resources.html

Robert Wood Johnson Foundation

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Chapter 7

A Global Perspective on the Care of Medically Vulnerable and Underserved Populations

Stephanie Taché, MD, MPH, Sarah Macfarlane, MSc, PhD, Megan Mahoney, MD, and Kevin Grumbach, MD

Objectives

- Describe the characteristics and distribution of medically vulnerable populations worldwide.
- Review common challenges faced by health systems globally in assessing and meeting the needs of medically vulnerable populations.
- Highlight best practices from across the world in how health systems are addressing the needs of medically underserved populations.
- Identify core competencies for health professionals to promote health equity locally and globally.

INTRODUCTION

Management of health care for medically vulnerable and underserved populations shares a common mission with the growing field of global health. The global health perspective "places a priority on improving health and achieving equity in health for all people worldwide."[1] Addressing the health needs of marginalized populations is fundamental to this orientation.

Care of domestic medically vulnerable populations represents a local facet of global health. The upstream causes of medical vulnerability and the health system challenges in locating those most at risk and providing them with appropriate and affordable health care are common across the world. Many students and health professionals with an interest in global health are also committed to caring for domestic underserved populations.[2,3] Framing the care of medically vulnerable and underserved populations in a global context opens opportunities to share solutions applicable to serving vulnerable populations in any country.

In this chapter, we use a global perspective to present unifying themes in addressing the needs of diverse underserved populations. We start by describing the causes, characteristics, and worldwide distribution of medically vulnerable populations. We then review health system challenges in assessing and meeting their needs, and illustrate solutions to some of these challenges from "best practices" from around the world. We conclude by describing competencies for health professionals to promote health equity locally and globally.

CAUSES OF MEDICAL VULNERABILITY WORLDWIDE

Nassoro, 7-year-old boy, lives in rural Tanzania and is undernourished. Because of severe droughts, he only receives one nutritious meal per day through the school program he attends.

Aisha, 9-year-old girl, lives in poor neighborhood of a large US city and is obese. Her family cannot afford to eat balanced meals and relies on a limited range of low-cost foods with high caloric, processed food of low nutritional value.

Several factors render populations vulnerable and result in health inequities, the greatest of which is poverty. For example, poverty results in food insecurity for millions of people across the world. Compounding factors contributing to health inequity globally include unhealthy and unsafe environments, destabilized societies and homelessness, and violation of human rights.

MALNUTRITION AND FOOD INSECURITY

Both under- and overnutrition result from food insecurity—the absence of enough, safe, nutritious, and socially acceptable food. Food insecurity may be chronic, seasonal, or temporary, and may occur at the household, regional, or national level. In low- and middle-income countries, the root causes of food insecurity include poverty, war and civil conflict, natural disasters, corruption, barriers to trade, low levels of education, and national policies that do not promote indigenous crop production for local consumption and equal access to food for all. In higher-income nations, the primary causes of food insecurity are poverty and public subsidies for mass-produced, agricultural mono-crops such as corn, which render high caloric processed foods less expensive than more nutrient-dense, perishable food, such as fruits and vegetables. A globalized food economy dominated by large agribusiness interests contributes to food insecurity across the world (see Chapter 26).

POVERTY AND ECONOMIC INEQUALITY

In 2010, 21% of the world's population lived on less than US $1.25 a day.[4] These 1.2 billion people live in absolute poverty deprived of basic human needs, such as access to food, water, sanitation, clothing, shelter, health care, and education. The burden of poverty has shifted from low- to middle-income countries. In 1990, 93% of the world's 1.8 billion poor lived in low-income countries, whereas today 72% of poor people live in middle-income countries.[5] Half of the world's poor live in India and China; one quarter in other middle-income countries, primarily Pakistan, Nigeria, and Indonesia; and only a quarter live in 39 low-income countries (Figure 7-1). Worldwide, poverty is no longer primarily due to a lack of resources in "poor" countries, but due to economic inequality in countries that, as a whole, are no longer impoverished.

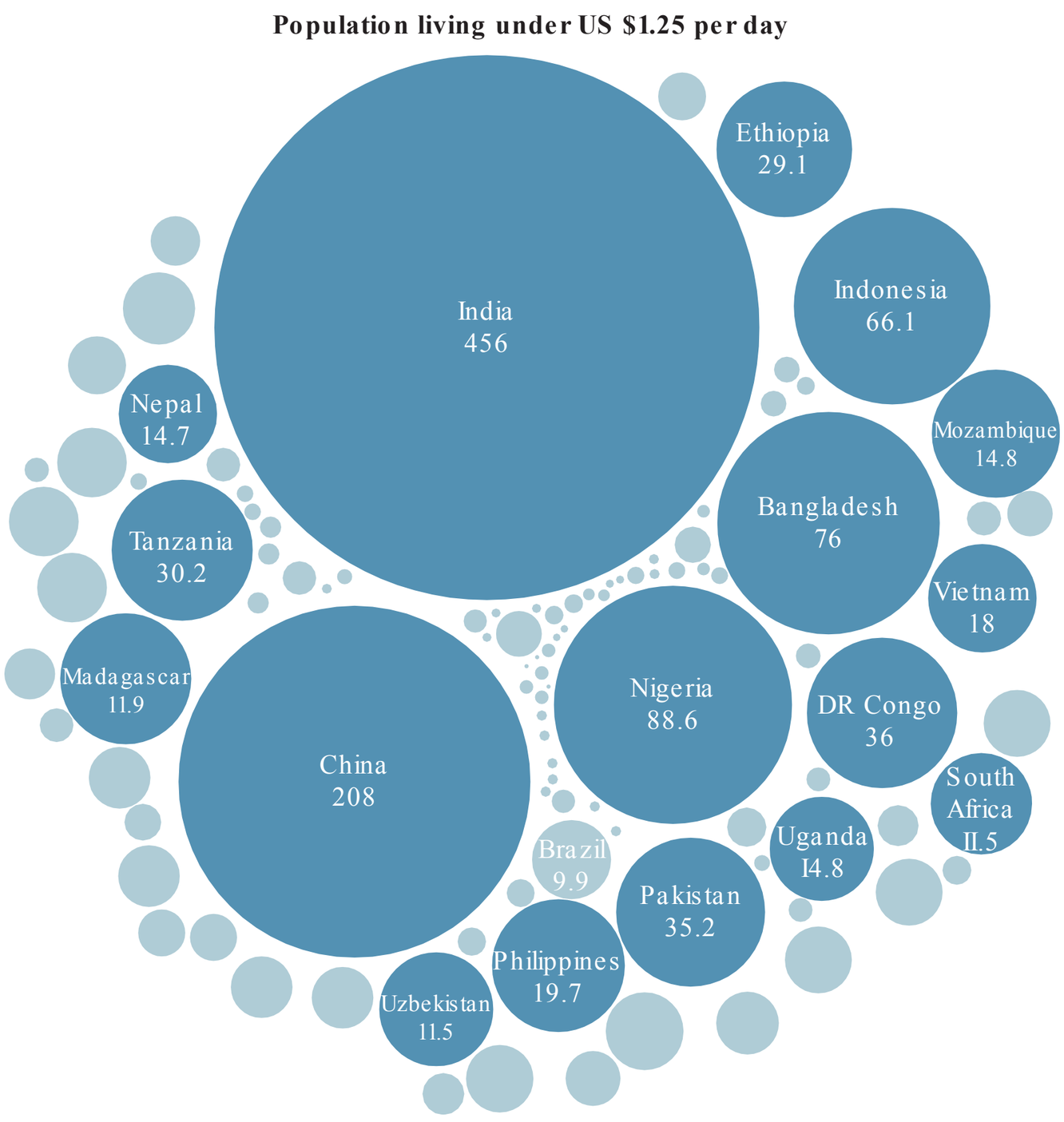


Figure 7-1. Distribution of worldwide poverty by country (in millions of people). (Data from Sumner.[5] Reproduced with permission from the Guardian Data Store.)

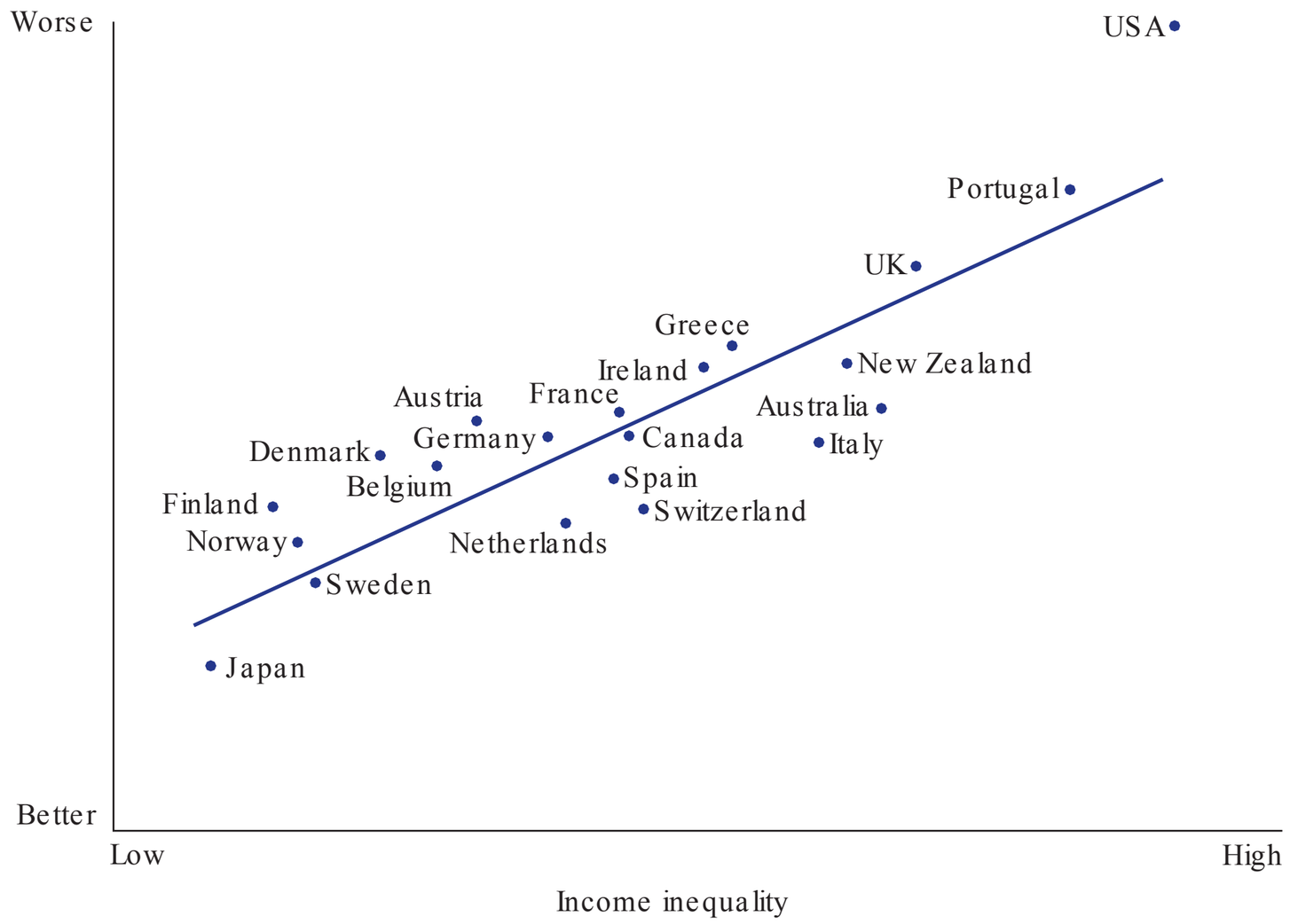


Figure 7-2. Relationships between the scale of income disparity and negative social attributes of a variety of health and social problems. (Source: http://www.slideshare.net/equalitytrust/the-spirit-level-slides-from-the-equality-trust.)

Poverty and health have a bidirectional association. Poverty leads to ill health because it forces people to live in environments that make them sick, without decent shelter, clean water, or adequate sanitation. Ill health, on the other hand, interrupts employment and can result in catastrophic household expenses that lead to poverty.[6] As noted in Chapter 1, relative income inequality, and not only poverty in absolute terms, adversely influences health. Individuals living in relative poverty in more unequal societies experience worse health outcomes as compared to those living in more equitable societies.[7] Within the Organization for Co-operation and Development, countries with greater relative income inequality have lower measures of physical health, mental health, drug abuse, obesity, teenage pregnancies, and child well-being, among other factors. Wilkinson and Pickett have demonstrated that among these countries, an aggregate measure of societal and health problems is worse in more unequal countries, with the United States faring particularly poorly in this regard (Figure 7-2).[8]

ENVIRONMENTAL RISK

Environmental factors account for an estimated quarter of the global burden of disease and disproportionally affect the poor.[9] Environmental risks include inadequate sanitation, indoor particulate exposure, and unsafe drinking water. For example, slum dwellers in urban areas in many nations do not have access to municipal water and sewage services, safe housing, health care, or other critical services. The rural poor face diminishing wildlife resources required for food.[10] Natural catastrophes such as droughts and floods are a subset of environmental risk, which often result in the displacement of populations. These catastrophes are becoming more prevalent due to global climate instability. Climate change is aggravating environmental risks such as increased exposure to heat stress, air pollution, respiratory allergens, and infectious diseases.

FRAGILE STATES, CONFLICT AND POSTCONFLICT SITUATIONS

Currently, one-third of the world's poor live in "fragile" countries[5]—countries undergoing postconflict or political transition, situations of prolonged crisis or impasse and deteriorating governance. For example, nations such as Syria and the Central African Republic have recently experienced a series of crises which have resulted in the collapse of the state, interruption of public services, and human rights violations.[11]

Conflict and its aftermath undermine the ability of a country to operate basic civic functions such as rudimentary security operations and health and social services, and to ensure economic opportunities for its citizens. Health facilities in conflict areas can disintegrate when supplies cannot reach them and when the lives and livelihoods of health workers are threatened. For example, 6 years after the 1992–1995 conflict in the Republic of Bosnia-Herzegovina, displaced Bosnians were 15% less likely to be working relative to nondisplaced Bosnians.[12]

Additionally, displaced men experienced higher rates of unemployment, and displaced women were more likely to drop out of the labor force, raising concern for the long-term economic vulnerability of displaced persons. The implication of having one-third of the world's poor living in fragile states is that normal health-care infrastructures cannot be relied on to reach medically vulnerable populations in these contexts.

Fragile states produce a ripple effect in high-income countries, as displaced persons often seek refuge in more economically and politically stable nations. For example, Europe is experiencing a surge of immigration from refugees seeking to escape traumatic conditions in the Middle East and North Africa, creating a humanitarian crisis challenging social, health care, and legal services. High-income countries also often have their own indigenously displaced populations in the form of homeless persons.

INTERNALLY DISPLACED POPULATIONS AND HOMELESSNESS

> Leila is a Syrian mother forced to flee her home with her two children because of civil conflict. She lives in a camp along the Turkish border in precarious living conditions.
>
> Tara is a homeless single mother of two who has fallen under the US federal poverty level because of catastrophic medical expenses. She lives in a homeless shelter for families.

Housing insecurity is multidimensional and describes a range of conditions including needing to move as a result of circumstances outside a person's control, instability in housing circumstances, or feeling unsafe within the home and its environment. Housing insecurity entails lack of privacy and comfort as well as lack of supportive relationships and connection to the local community. Underlying all dimensions of housing insecurity is a perceived lack of control over circumstances of life, including finances, employment, health, and family stability. The consequence of living with this combination of insecurities leads to focusing on day-to-day survival. Poor housing conditions have been linked to multiple negative health outcomes in both children and adults. Housing insecurity has been associated with poor health, lower weight, and developmental risk especially in children.

DISCRIMINATION AND HUMAN RIGHTS VIOLATIONS

Discrimination and human rights violations adversely impact health across the globe. People face discrimination based on many factors, including race, religion, gender, age, and sexual orientation, often leading to severe violation of human rights through forced labor practices, absence of free movement or free speech, and torture or degrading treatment. Many individuals are subject to virtual slavery through illegal forced labor practices, to which children are particularly susceptible.[13,14] Officially sanctioned discrimination with egregious denial of human rights occurs in some countries, such as the recent legislation in Uganda imposing harsh criminal penalties for homosexual acts and educational outreach. But discrimination in various forms is ubiquitous in cultures and societies across the globe. Systematic violations of human rights are often coupled with outright denial of access to health care or marginalization of populations in a manner that impedes access to care.

Human rights violations do not necessarily respect national borders. An example is human trafficking—trade in humans, most commonly for the purpose of sexual slavery, forced labor, or commercial sexual exploitation.[13] The United States is a major destination country for human trafficking, with 14,500–17,500 victims trafficked into the United States annually.[15] The health consequences of human trafficking include sexually transmitted infections, including HIV, and permanent damage to reproductive organs.[16] Victims of trafficking often have psychological trauma, resulting in chronic anxiety, depression, sleep disorders, and posttraumatic stress disorder. Victims may be coerced into, or willingly surrender to, drug use in an attempt to alleviate their distress.[17] Perpetrators of sex trafficking often prevent their victims from accessing health services. When victims do seek care, they may be inhibited from revealing their circumstances due to fear of reprisal.

HEALTH SYSTEM CHALLENGES

Many countries fall short of being able to provide even the most basic package of essential medical services to vulnerable populations. The reasons for this include difficulties for health services in locating and serving some population groups, lack of appropriately trained and deployed health-care personnel, inadequate health information systems, and lack of political will to achieve universal health-care coverage.

"THE SCANDAL OF INVISIBILITY"—LACK OF DOCUMENTATION

Health systems have difficulties tracking the health and health-care needs of people who do not have official records. Many people, particularly those born in rural regions of low-income countries, have never been included in national civil registration system; others drop off registration systems when they migrate without formal documentation or sanctioned residency status. Setel et al[18] have termed this a "scandal of invisibility," noting that

"Most people in Africa and Asia are born and die without leaving a trace in any legal record or official statistic." In 2003, only 60% of children were registered at birth in developing countries compared with 98% in industrialized countries. In developed countries, invisibility is often caused by cross-border migration. In 2010, about 4% of persons living in the United States and 5% of the US labor force were individuals without authorization to reside in the country.[19] Many of these undocumented immigrants avoid using health services because of fear that this may lead to deportation or otherwise jeopardize their ability to gain legal residency status.

Without official records, it is difficult for a health system to perform proactive health planning and reach out to provide services for people lacking documentation. In many developing countries without universal population registration, clinics send community health workers to visit households in their geographic catchments areas to provide members with health records and encourage them to attend clinic visits. In the United States, community health centers frequently make similar efforts to reach out to undocumented populations to deliver health care.

WORKFORCE SHORTAGES AND MALDISTRIBUTION

Poor people in most countries rely on publicly operated health-care services, and these facilities are often challenged by extreme shortages of medicines, equipment, and adequately trained human resources. The World Health Organization estimates that "the world will be short of 12.9 million health-care workers by 2035."[20] Ethiopia, for example, has an average of 0.3 physicians per 10,000 people compared with the United States, which has a supply of 24.2 per 10,000 people.[21] Yet, even in the United States,[22] some analysts estimate a shortage of 124,000 full-time physicians by the year 2025.

Even when total supply is adequate, almost all nations experience maldistribution of health workers between urban and rural areas and, within urban areas, between more and less socioeconomically advantaged communities. In 2010, a total of 65 million individuals in the United States lived in areas designated by the federal government as medically underserved areas.[23] In low-income countries and middle-income countries with low overall supply of health workers, inequities in the distribution between urban and rural areas are particularly pronounced. In Brazil, Niger, and Pakistan, for example, in 2005 the urban and rural supply of physicians, nurses, and midwives per 10,000 population were 52.8 and 9, 10.6 and 0.7, and 22.1 and 6.4, respectively.[24] Among those working in underserved areas in developing countries, many are inadequately trained to carry out the roles they are expected to fill. For example, in Tanzania, two nurses may staff a typical rural health center, while a nonphysician medical officer with only 4 years of training may run the nearest hospital.

INADEQUATE HEALTH INFORMATION SYSTEMS

Health information and surveillance systems are essential to planning the equitable distribution of services, but are inadequately maintained in many low- and middle-income countries.[25] Health facilities track information about the services they provide, but it is more difficult to assess the needs of populations who do not access services. National surveys such as demographic health surveys[26] provide a cross-sectional view of the geographic and socioeconomic factors associated with the prevalence of health problems but often do not assist in assessing the needs of those most at risk. For example, they often do not include noncommunicable diseases such as mental health, cancers, heart disease, and diabetes in many low- and middle-income countries. Few disease registries exist in African countries, making it almost impossible to locate and follow up people with early stages of diseases such as cancer.

LACK OF UNIVERSAL HEALTH-CARE COVERAGE AND UNAFFORDABILITY OF CARE

Millions of people around the world cannot afford to pay for medical care. Many of those who do seek care suffer financial catastrophe and impoverishment because of meeting these costs.[27] This occurs in both rich and poor countries. In many countries, the right to health care remains an employment benefit, restricted to the salaried workforce. There are approximately 150 million uninsured people who suffer financial catastrophe each year around the globe, with 100 million pushed under the poverty level simply because they need to pay for the health services they use.[27] As discussed in Chapter 2, the financial risk associated with being uninsured is a form of vulnerability.

- Failure to sufficiently consider the local context, in particular that of domestic health disparities as an essential aspect of global health.
- Prioritizing disease-specific interventions in low-income countries, not health-care systems improvement for the poor in middle-income countries.
- Implementing evidence-based health interventions without contextual adaptation.
- Failure to integrate an isolated health experience abroad within a broader global health context.
- Implementing community health programs without engaging the community and government partners.

HEALTH SYSTEM SOLUTIONS

Health systems can take actions to mitigate the negative effects on health of social and environmental disadvantage. In this section, we highlight several strategies that have global relevance for addressing vulnerability and provide examples from different countries of effective solutions that are within the control of the health sector.

BUILDING PRIMARY CARE SYSTEMS

Expansion and reinforcement of primary health-care systems can partially alleviate health inequity in countries with income inequalities. Strong primary health care is associated with better health and a more equitable distribution of health care both cross-nationally and within nations.[28]

Cuba uses a "community-oriented primary care"[29] approach to provide health care. A team consisting of a family physician and nurse provides primary health care to a defined local population, working out of neighborhood clinics serving approximately 600 neighborhood residents per team. Medical records are organized by family and health data regularly recorded, with public health officials visiting each clinic to review and discuss the data. This highly structured, prevention-oriented system has produced impressive outcomes. Vaccination rates in Cuba are among the highest in the world. Life expectancy is 78 years and infant mortality has fallen to less than 5 per 1000 live births in 2013, rivaling those of many more economically developed nations.[30]

Brazil's Unified Health System involves transdisciplinary collaboration. Medical providers deliver primary care alongside community health workers implementing public health interventions.[31] Providers use data-driven decision making in assessing the impact of environmental and social determinants of health by incorporating input from patients and communities and research findings into diagnosis and treatment. Community health workers obtain these data at the community level. Health outcomes have demonstrated decreased rates of infant mortality from 1996 to 2004[32] and hospitalizations from 1999 to 2007.[33]

APPLYING mHEALTH

The increasing numbers of mobile phone subscribers, even among poor and rural populations, has led many countries to consider how to take advantage of mobile phone technology to deliver health care. mHealth interventions are particularly helpful in overcoming barriers to accessing health care associated with lack of transportation, health-care workforce shortages, and inadequate medical records.

Health systems in low- and middle-income countries use mHealth to connect frontline providers with patients for transfer of patient medical information, health promotion, health education, disease prevention, disease screening and monitoring, self-management of chronic illnesses, and support for adherence to treatment.[34] For example, FrontlineSMS is an open-source platform for two-way data exchange between a laptop computer and mobile phone. It allows communication of health problems between residents of remote and medically underserved areas and their service providers who would not otherwise have significant access to these populations. Public health messages can be sent through this data hub via short message service (SMS). Many low- and middle-income countries have adopted this system, including Malawi, Bangladesh, and Honduras.[35,36] A multisite randomized clinical trial in Kenya of HIV-infected adults initiating antiretroviral therapy demonstrated that patients receiving SMS text messaging support had significantly improved adherence and viral control.[37] Similar innovations in mHealth are being piloted in high-income countries to reach vulnerable populations. For example, a randomized clinical trial of motivational text messaging among elderly urban African Americans in the United States demonstrated increases in physical activity.[38]

ADDRESSING WORKFORCE SHORTAGES

While many countries face shortages of trained health-care personnel to deliver basic health-care packages, some have managed to bridge this gap through the deployment of community health workers. Community health workers have been shown to improve health-care access and outcomes, strengthen health-care teams, and enhance quality of life for people in poor, underserved, and diverse communities.

Pakistan's health sector is characterized by major workforce shortages and urban–rural maldistribution. The Lady Health Worker Program was created to address this problem. Lady health workers (LHW) are women from local communities with at least 8 years of formal education, who receive 6 months of special training to provide basic primary health-care treatment and preventive services and act as liaison between the formal health system and the community. LHWs provide essential drugs for treatment of minor ailments such as diarrhea, malaria, acute respiratory tract infection, intestinal worms and contraception, and immunizations for women and children. The program covers almost 60% of the nation's population with more than 90,000 LHWs throughout the country. Indicators of neonatal and child mortality have shown significant improvement in areas served by LHWs.[39]

ACHIEVING UNIVERSAL HEALTH-CARE COVERAGE

Many countries still fall short of providing universal entitlement to health-care coverage, particularly low- and middle-income countries with limited financial

Table 7-1. Improvement in Two Health Outcome Measures in Mexico After the Introduction of the Segura Popular Program[40]

	1990	2010	Reduction in Mortality Indicator among Population Groups Newly Insured by Seguro Popular Program	Reduction in Mortality Indicator among Population Groups Previously Insured
Under 5 mortality	47.1 per 1,000 live births	16.7 per 1,000 live births	11%	5%
Maternal mortality	90.4 per 100,000 live births	51.5 per 100,000 live births	32%	3%

resources. The Mexican experience is an example of successful implementation of coverage expansion in a middle-income country. A national health insurance program, Seguro Popular, introduced in 2003, has provided universal financial access to a package of comprehensive health services. The program represents a transition from the preexisting model of social insurance for health care limited to employed individuals to more universal social protection of health as a right based on citizenship. More than 50 million Mexicans previously without insurance coverage gained access through Seguro Popular to essential health services, including catastrophic illness coverage. Comprehensive investment in child health in particular resulted in the number of insured children[40] increasing from about 800,000 in 2007 to 5.8 million in 2011. Health outcome indicators improved during this period, with previously uninsured populations demonstrating the most benefit (Table 7-1).

CARING FOR DISPLACED POPULATIONS

During episodes of mass human migration, such as occur when people flee a region due to conflict, famine, or natural catastrophes, special measures must be set in place to provide care in the absence of basic health infrastructure. One example of how to provide health services in this context was a mass vaccination campaign in South Sudan. In 2012, an estimated 160,000 refugees fled from Sudan to neighboring South Sudan as a result of ongoing conflicts in the region. From the end of December 2012 to the second week of February 2013, the Ministry of Health of the Government of South Sudan introduced a two-dose oral cholera vaccine in four refugee camps as a preemptive strategy to prevent cholera. The overall coverage of the first round in the camps was 92%, while the vaccination coverage achieved during the second round of the campaign was 89.4%.[41]

EDUCATING HEALTH PROFESSIONALS

The 2010 report, Transforming education to strengthen health systems in an interdependent world, describes a new era of educational reform in global health.[42] Many of the recommendations, including the need for competency-based curricula, creative use of information technology, transformative learning, interprofessional teamwork, and a systems approach to institutional reforms, are particularly suited to preparing health professionals to care for underserved populations. A common set of skills are applicable to working with vulnerable populations in diverse contexts across the globe, including in developed nations. Current approaches to training emphasize this global–local connection (Table 7-2).

In light of the profound health professional shortages and resource-constrained educational environment in most low- and middle-income countries, building domestic workforce capacity is a major need in these nations. Although the provision of health services by international nongovernmental organizations has value, sustainable improvement in health care and public health in these countries requires low- and middle-income countries to develop greater self-sufficiency in health professions education and workforce deployment. International funding agencies have started to invest in strengthening health professional training at educational institutions in low- and middle-income countries. For example, the Medical Education Partnership Initiative (MEPI) funded by US federal agencies and administered by the Fogarty International Center supports educational initiatives in sub-Saharan Africa with the goal of producing 140,000 additional health-care workers in these nations. Grants encourage institutions to come together in consortia to share

Table 7-2. Core Competencies: Competencies That Are Applicable to Working with Vulnerable Populations in Diverse Contexts Worldwide

1. Demonstrates optimal resource management and mobilization, including cost-effective, evidence-based care
2. Able to deliver team-based prevention and care with excellent interprofessional skills
3. Practices as a health advocate at an individual and community level, as well as an advocate for health systems reform
4. Collaborates in a transdisciplinary and multisectoral fashion
5. Communicates and interacts with a high level of cultural acumen, flexibility and adaptability
6. Incorporates principles of change management
7. Collects and maintains information to inform delivery of preventative and medical care

training strategies and best practices, often in collaboration with educational institutions in the United States and other high-income countries. MEPI has encouraged more training to be located in rural sites, to address workforce maldistribution within these countries.[43]

CONCLUSION

A global perspective on health professions education calls for greater integration of global and local training initiatives addressing underserved populations. This chapter has emphasized the commonalities in root causes of health inequities across the globe, and in approaches to addressing these inequities. Health professions training curricula should reinforce the common themes and competencies for addressing health inequities globally and locally, and not overlook opportunities for students and trainees interested in global health to engage with local underserved communities in addition to having educational experiences with vulnerable populations abroad.

Medical vulnerability is a global phenomenon with close ties to poverty. Although the distribution of poverty has changed over time, poverty remains one of the most powerful contributors to vulnerability across the world. Many other social and environmental determinants of health and health inequity, such as food and housing insecurity, environmental exposures, and discrimination, are shared among populations living in nations of very different levels of overall economic development. Similarly, health systems face common challenges in assuring universal access to care, appropriate supply and distribution of the health-care workforce, and assessing the health and health needs of the vulnerable populations. At the same time, many nations—including less economically advantaged countries—have implemented best practices in their health sectors, such as expanded health-care coverage, community-oriented primary care models, and deployment of community health workers, that have improved population health and health equity. A global health perspective in the training of health professionals must emphasize these commonalities and integrate a global–local approach to addressing the needs of underserved populations.

- Care of domestic medically underserved populations is a local facet of global health.
- Poverty is a unifying factor in rendering medically vulnerable populations. Other factors associated with vulnerability include environmental degradation, political instability, and human rights violations.
- Although most medically vulnerable populations around the globe live in low- and middle-income countries, pockets of underserved populations can increasingly be found in high-income countries with large income disparities such as the United States.
- Health systems face common challenges in assessing and meeting the needs of medically vulnerable populations globally. These include insufficient and inadequately trained workforce, lack of universal health-care coverage or unaffordability of care, and lack of data systems to track or identify populations in need.
- Some best practices that address the needs of medically underserved populations include use of community outreach workers to improve health-care access in remote and underserved areas, use of mobile technology for effective communication and timely transmission of information, and effective health policies based on the political will to provide universal health insurance and strengthen primary care systems.

We suggest the following selection of competencies required in caring for the medically vulnerable in global and local settings:[44,45]

- Understand the relationship between social determinants of health, health equity, social justice, and how these vary in low-resource settings globally.
- Understand health-care delivery strategies in low-resource settings, in particular the role of community-based health-care and primary care models.[45]
- Maintain and use reliable health information systems to inform practice and policy.
- Tailor health outreach and clinical interventions by taking into consideration local socioeconomics, politics, health disparities, and cultural influences.[44]
- Demonstrate the ability to communicate effectively and collaborate with the patient, the patient's family, and/or caregivers, with sensitivity to sociocultural and health literacy issues.[44]
- Demonstrate the ability to use interpreters effectively when language represents a communication barrier.[44]
- Demonstrate the ability to work effectively within a multidisciplinary team, including through transprofessional collaborations.

DISCUSSION QUESTIONS

1. In this chapter, we review some of the social determinants of health affecting underserved populations both in the United States and abroad. What other factors affect the underserved worldwide?
2. The United States experiences high levels of obesity compared with other countries. Describe the occurrence

of other global health conditions or public health problems that have a high prevalence the United States.

3. Many developing countries now face a "double" burden of disease consisting of both infectious and chronic medical conditions. Discuss whether this double burden of disease also affects medically vulnerable and underserved populations in the United States, and how it is manifested.

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Chapter 8

Advocacy

Ricky Y. Choi, MD, MPH, Laura Gottlieb, MD, MPH, and Alice Hm Chen, MD, MPH

Objectives

- Define advocacy.
- Describe levels of advocacy in the care of underserved and vulnerable communities.
- Illustrate ways health professionals can engage in advocacy.
- Provide a menu of activities for community advocacy.

Michael lives with his family in North Richmond, California, a city with five oil refineries. His 6-year-old daughter has been to the emergency department three times in the past few months for respiratory complaints, as have many of her classmates at school. Michael's bronchitis has been lingering for quite some time and last year he had a heart attack. The refineries are known to release high levels of air pollutants including carcinogens and chemicals that cause respiratory and neurologic problems. Michael suspects that the pollution spewing from the refineries contributes to illness in the community. Michael's wife is pregnant and he worries about harmful effects of the pollution on his unborn son. Because North Richmond is his home and he cannot afford to live anywhere else, Michael feels frustrated and helpless.

INTRODUCTION

The term "advocacy" often conjures images of rallies, marches, and protests. But at its core, advocacy is an activity on someone else's behalf directed toward a specific goal. For the health professional, the "goal" and the "someone" are clear: a better state of health for patients.

Medical professionals' obligation to advocate for their patients is often conceived as a fundamental professional duty. Entrusted with the details of patients' life, their hopes, and concerns, medical providers are obligated to use this intimate knowledge to their patients' benefit. Although doctors, nurses, and other health professionals engage in daily advocacy on behalf of their patients (for example, helping patients obtain medications or disability benefits), aspirational definitions of physician, and other health professional roles include not only the promotion of the health of individual patients but also of society as a whole.

In its Declaration of Professional Responsibility, the American Medical Association declares, "humanity is our patient." Physicians are asked to pledge to "…respect human life and the dignity of every individual; …and to …advocate for social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being."[1] The American Nursing Association likewise defines nursing's role as "… alleviation of suffering …, and advocacy in the care of individuals, families, communities, and populations."[2] In this chapter, we focus on these broader community and population advocacy efforts, explore the roles clinicians can play, and present practical advocacy tools.

TYPES AND LEVELS OF ADVOCACY

Clinician advocacy starts with providing care that integrates the full spectrum of a patient's needs. Examples include helping patients navigate complex health care systems,

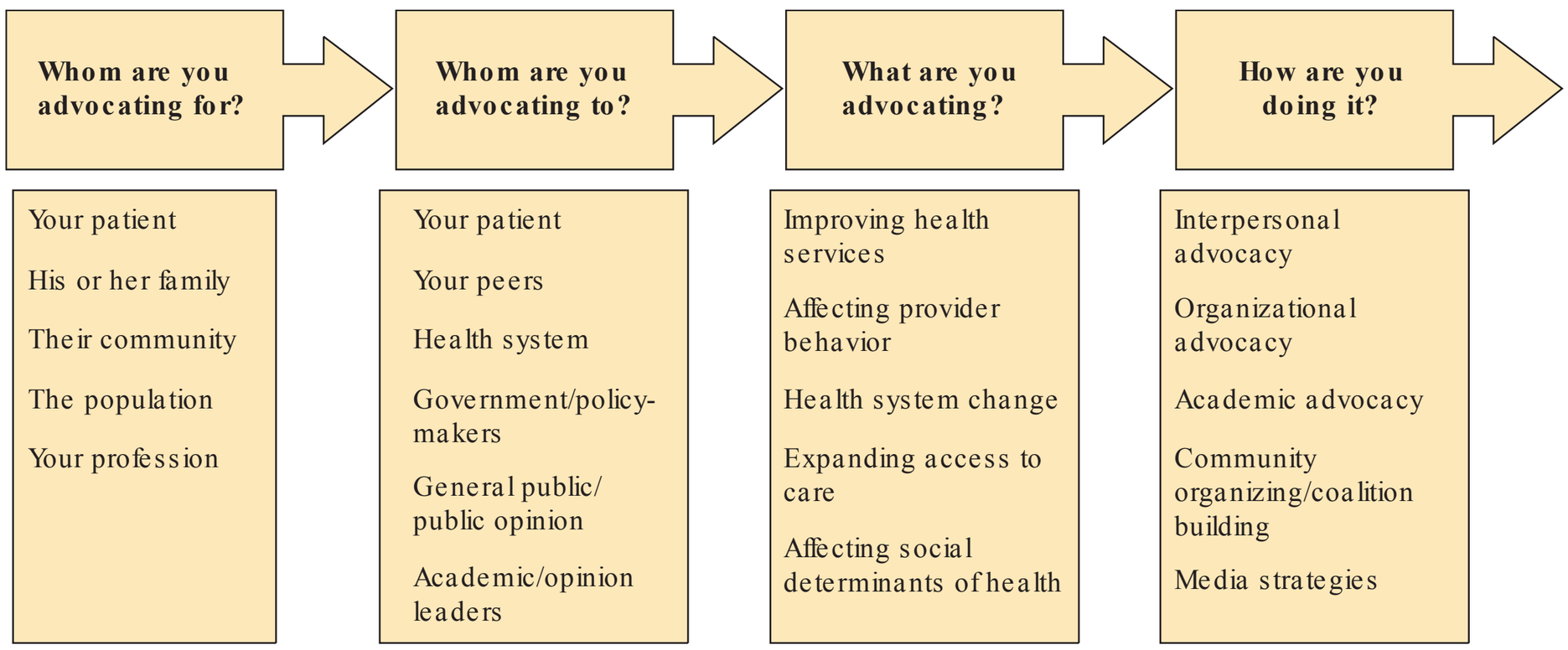


Figure 8-1. Recognizing levels of advocacy. (From O'Toole T. Advocacy. In: King TE Jr, Wheeler M, Bindman A, Fernandez A, Grumbach K, Schillinger D, Villela T. (eds). Medical Management of Vulnerable & Underserved Patients: Principles, Practice, & Populations. New York, NY: McGraw-Hill, 2007:429-436.)

asking pharmacies and insurance companies to cover specific medications, and referring patients to social service agencies.

Advocacy at the individual patient level is a core component of every provider's professional obligations. However, this obligation extends beyond the provision of good clinical care to a responsibility to address systemic inequities and abuses as well. At the institutional level, for example, clinical providers can be instrumental in advocating for system changes that improve care. Examples of institutional advocacy include convincing the hospital leadership to expand interpreter services or to institute more generous charity care policies.

Health-care advocacy targeting health-care system policies or societal laws governing health care is another level of health-care activism. Advocacy may take the broad form of support for a single-payer system or research into areas of political contention, like use of needle exchange to prevent HIV transmission. Providers may advocate on behalf of patients by acting to change health-care regulations, such as protesting against the imposition of short hospital stays for obstetrical deliveries, or challenging gag laws that prohibit them from informing patients of therapeutic options not covered by their insurance or inquiring about firearms in the home.

Another level of health professional engagement is community-based advocacy, which can have an impact on the broader population beyond the patients seen in any particular health-care setting. Medical professionals and their patients have advocated for changes in policies from support for social welfare programs, food policy, public support of housing, education, and prison reform to increased funding for research and health-care delivery for diseases from HIV to Parkinsonism.

While we use a framework of clinician, institutional, healthcare and community level advocacy, thee are other ways of categorizing advocacy efforts. Some define advocacy in terms of audience, issue, and method (Figure 8-1). Others have proposed distinguishing between the levels of advocacy calling working on behalf of the interests of a specific patient "agency" and reserving "activism," for efforts directed at changing social conditions that undermine health, particularly those that undermine population more than individual health. Agency, in this schema, is "about working the system, engaging in activism is about changing the system."[3]

Medical research can also be conceived of as another form of advocacy. Indeed, research is one of the professions' most powerful tools to change both the delivery of care to individuals and influence broader public policy. Beyond documenting best practices in health-care delivery and advancing scientific knowledge, medical research also has been pivotal to supporting broader social change as well. From supporting bans on smoking in public places to defining disparities in health and health care, research has documented problems related to health and served as foundation for changes in public and professional opinion, health-care delivery, medical education, and public policy.

ADVOCACY FOR THE UNDERSERVED

Advocacy is particularly important for patients from underserved and vulnerable communities because they often face additional social and economic barriers that impede health.[4-7]

As discussed in Chapter 1, more than 70% of premature mortality is caused by behavioral, social, and environmental factors, including housing conditions, food availability, and access to health care.[8] The ability to influence these social factors (e.g., choosing to live in a safer

neighborhood or finding a higher paying job) is a function of the power to change one's circumstances. Those living in marginalized and underserved communities are not only more likely to be sick but also less likely to be able to change the conditions that make them sick. For example, those living in homes exposed to toxic chemicals from a local oil refinery—like Michael in the opening case study—may have few options to relocate.

BARRIERS TO ADVOCACY

Since social factors can contribute to poor health status and be barriers to following through with therapeutic plans, provider advocacy activities directed at upstream social and environmental factors could play a significant role in shaping health and illness. While health professionals working in underserved settings typically recognize the importance of community advocacy, there are a range of obstacles that can prevent them from engaging on the population level.

According to a physician survey conducted by the Robert Wood Johnson Foundation, four out of five physicians think patients' social conditions are as important to address as medical issues.[9] However, according to the same study, a similar number reported that they did not feel confident in addressing the social needs of their patients.

Another study reveals that more than 90% of physicians surveyed believe that public roles are important and over three quarters of providers believe it is very important to be involved in issues connected to patients' health, including issues such as tobacco control, road safety, and poor nutrition. Nevertheless, most of the providers surveyed were not involved with local community or medical organizations or political issues related to health.[10]

Moreover, compared with the general public, physicians are less likely to exercise their right to vote, a potential indicator of community engagement.[11] Voting is a fundamental way to contribute to community decision making, including on health-related initiatives such as a tobacco tax. There are few data explaining why, as a group, health-care providers show low levels of civic engagement. Proposed reasons include not feeling competent to address issues outside of clearly defined clinical problems and a lack of time.[12] When physicians do feel that they are "experts" in a field, however, there is evidence that they are often involved in policy discussions. In one survey of academic physicians, over half of those who responded reported that they were engaged in at least one of three types of policy-related activities: policy-related research, expert advice to government officials, and collaboration with organizations to advocate for public policy.[13]

Although it is generally conceded that health professionals have the authority to shed light on matters influencing health granted to them by their intimate contact with patients, some question whether this authority translates into an obligation.[1] Even in very concrete ways, like caring for patients from underserved communities, the obligation to engage in wider social issues is not universally accepted by medical professionals. Over 30% of US physicians, for example, do not accept patients covered under Medicaid, the insurance for the poor.[14] Furthermore, the role and responsibilities of the individual provider are often contrasted with that of the medical profession as a whole, with advocacy toward patients (the agency described earlier), falling under the responsibilities universally acknowledged of the individual provider, and "activism" toward changing social causes of disease as a responsibility of the profession.[1]

As a profession, much of medical advocacy has been focused on self-interested issues rather than on larger societal ones. Lobbying for issues benefiting medical providers (i.e., better reimbursement, fewer regulations) are often framed, appropriately or not, in terms of patient care, safety, and outcomes. Physicians in politics, with some notable exceptions (e.g., Chile's Michele Bachelet) have often done more to protect the privileges of their social class than advocate for the needs of the vulnerable, advocating for policies that cut funding to the social safety net and oppose universal health insurance, for example.[15]

Despite a lack of confidence in their ability to effect change in broader community issues and a spotty history of doing so, health-care professionals are uniquely positioned to engage in community advocacy. In addition to their unique vantage point, health-care professionals continue to enjoy a high level of trust among Americans. In a recent national poll, nurses, pharmacists, and physicians comprised three of the four top-ranked professions for honesty and ethical standards.[16] As trusted leaders in the community, health professionals have an opportunity to advocate for change and are regarded as highly valued partners by community advocacy groups.

- Health professionals may fail to recognize the broader social and environmental factors that make patients sick.
- Health professionals often feel ill equipped to address nonclinical factors that contribute to patients' health.
- Health professionals are less likely to engage with health-related issues at the community level, such as through civic engagement and working with community organizations.
- Health-care providers have been more engaged in efforts for self-interested gains than in broader social issues.
- Many health-care providers define their public role narrowly.
- Broader social activism is considered a responsibility of the profession rather than the individual provider.

The staff at Michael's clinic is astounded at the number of patients they see with asthma. They establish a special asthma clinic, an asthma nursing hotline and a program to visit and assess environmental asthma triggers in patient homes. They document all the hospitalizations for asthma from their clinic. The clinic contributes data to the department of public health and providers join efforts to advocate for higher standards of pollution control. Comparing these rates with the lower rates of hospitalizations for asthma in more affluent areas and using Michael's daughter's multiple visits to the hospital as an illustration, one nurse writes a letter to the editor of a local paper.

COMMUNITY ADVOCACY ACTION STEPS

IDENTIFY THE PROBLEM

Community advocacy begins when an unresolved problem requiring intervention beyond the scope of typical practice is identified in the course of patient care. Examples abound of health professionals who noticed a problem among patients who they served and "connected the dots" to advocate for changes at the community level to address the underlying behavioral, social, and environmental determinants of these problems. Research and data collection is often the place many health-care advocates begin, but their efforts to improve health should not end there. Dr. Abraham Jacobi, regarded as the father of pediatrics in the United States for his pioneering advocacy for child health in the latter part of the 19th century, witnessed the ill effects of malnutrition and the consumption of unpasteurized milk on children in his practice. He became an outspoken promoter of breastfeeding and one of the first to advocate that raw milk is safer to drink after boiling.[17,18]

The Australian neurosurgeon Kenneth Jamieson identified the social and behavioral factors contributing to motor vehicle-related trauma mortality among his patients; he advocated among surgical professional societies and government for regulatory policies to address these social determinants, culminating in Australia becoming an international leader on helmet and seatbelt laws and limits to drivers' blood–alcohol levels.[19-21]

A more contemporary example comes from Marilyn Stebbins and Helene Lipton, faculty at the University of California, San Francisco School of Pharmacy, who recognized that many underserved elderly patients were not getting medications that they had been prescribed because they found it difficult to understand and navigate the complex pharmacy rules in their Medicare "Part D" coverage. They developed a successful national model where pharmacy students perform outreach to Medicare Part D recipients to educate them about the Part D program and help them access affordable medications.[22]

TARGETS AND TOOLS FOR ADVOCACY

Once a problem is identified, advocates must identify targets for advocacy efforts and a strategy to impact those targets. Advocates can select from a range of targets and strategies including examples given in Table 8-1.

Some of the most effective agents for community health improvement, such as Dr. Jacobi and Dr. Jameson, worked at multiple levels and simultaneously engaged in advocacy with policymakers, health-care institutions and organizations, and the public.

Table 8-1. Advocacy Targets and Strategies

Target	Advocacy Type	Potential Strategies
Laws	Legislative advocacy	Support legislation or ballot measure, lobby officials, vote, testify at a hearing Example: meet with an elected official to discuss a bill that would expand Medicaid coverage to undocumented resident.
Government agency	Regulatory advocacy	Assist agencies in writing or changing regulations Example: propose "meaningful use" regulations that accommodate for low internet use among patients who seek care at safety net hospitals
Health-care institutions	Institutional advocacy	Lead change in a leadership position or as a committee member; work with a professional society to influence practice Example: improve access to interpreter services in a health-care setting
Public	Public advocacy	Initiate an education campaign, hold a rally, demonstration, or press conference, start or participate in media or social media campaigns, and/or write opinion pieces Example: wage a campaign to tax sugary drinks

COMMUNITY ADVOCACY TOOLS

Advocacy can be time sensitive and time consuming and thus difficult to incorporate into the schedule of even the most impassioned health professional. Some advocacy opportunities such as public hearings, appointments with public officials, or media interviews may occur only during typical work hours. Fortunately, advocacy activities can often be performed outside of clinical hours, and can involve short- or long-term commitments depending on the level of interest, skills, and availability of the advocate (Table 8-2). Here, we focus on five tools that may make advocacy activities more accessible to busy health professionals (Table 8-3). These tools can be used to reach different target audiences for advocacy, including the general public, policymakers, and professional organizations (Table 8-1).

1. Letters to the Editor

Many newspapers reserve a section for the public's response to their reporting and other current events. There are frequent opportunities to respond to articles featuring health care. Many people, particularly influential decision makers, regularly read the letters to the editor section to gauge public opinion. Because print space in a newspaper is limited, letters are typically concise (150–200 words), so every word must count (see Box 8-1). If you enjoy the experience of writing a Letter to the Editor, consider writing a longer submission in the form of an opinion piece (see "Public Medical Writing" section).

Table 8-2. Examples of Health Professional Community Advocacy Activities

Episodic	Longitudinal
• Write a letter to the editor • Publish an opinion piece for traditional media, social media, or health professional journal • Call or write to a legislator • Testify at a hearing • Meet with an elected official • Prepare a news brief • Donate money to a campaign or individual • Vote • Participate in or organize a voter registration drive • Phone bank on an issue • Start or join a social media campaign, create a Web site • Host a fundraiser for a candidate for office	• Run for elected office • Conduct research on policy-related science • Serve as a health advisor to a legislator or media contact • Teach advocacy skills to students in the health professions • Serve on the board of directors for a professional or community organization • Form a community coalition • Start or work for a nonprofit • Take a leadership role in your professional society • Lead a health-care organization

Table 8-3. Advocacy Tools for Health Professionals

Letters to the Editor
- A concisely written response to a newspaper about a recent article or an issue facing the community
- Commonly read by decision makers to gauge public opinion

Public Medical Writing
- A longer form narrative to be published by outlets such as a medical journal, local newspaper, blog, or a community weekly
- An advocacy format to share personal experiences and present an argument

Social Media Campaign
- The use of social media (i.e., Facebook, Twitter, Tumblr) to broadcast an advocacy message
- A format to build a like-minded community and to communicate directly to influencers.

Lobbying
- Meeting to educate and persuade an elected official on an advocacy position
- Developing a relationship and offering oneself as a resource to an elected official.

Organizational Involvement
- Involvement and leadership in a professional society or advocacy organization
- A forum to meet like-minded colleagues and coordinate activities for larger scale change.

2. Public Medical Writing, Including Op-Ed Pieces

While the world of health care is often dominated by data discussions, and data are often pivotal to sparking change, combining data with personal experiences may have a powerful impact on both key decision makers and the public at large (see Box 8-2). Health professionals often

Box 8-1. Helpful Hints for Writing a Letter to the Editor

- Know your subject well.
- Be sure to adhere to the guidelines set forth for letters to the editor by your target media outlet. Guidelines for submission will be on the publication's website.
- State the title of the article you are responding to, the issue, and your unique perspective with one or two points. Highlight your credibility on the topic with phrases such as "As a doctor" and "I have patients who are affected by."
- Do not depend on anecdote alone: use an "evidence-based" approach for more credibility.
- End the letter with your recommended next steps, your "call to action."
- Submit the letter within 24 hours from when the article was published (because the news cycle is short).
- If your letter is published, share it widely with your contacts. If you are seeking to influence a legislator or organization, clip the article and mail it with a cover letter to the targeted person or agency.

Box 8-2. Helpful Hints for Writing an Opinion Piece

- Identify a temporal "hook" that makes your issue relevant; this can be a current event or a more predictable event like "World Diabetes Day."
- Have a memorable first sentence or two (a "lead") that will entice the reader to keep reading. A unique, unexpected, provocative, or personal perspective is more likely to be accepted.
- Stay within the recommended word limits (typically 750 words for a newspaper opinion), and keep a sharp focus on your topic.
- State the source of your authority—professional or experiential.
- Anticipate objections to your point of view and frame your argument accordingly.
- Include a specific "ask" or recommendation at the end of the piece.

have direct personal experiences that encapsulate an issue far more persuasively than data and statistics. There are myriad outlets for opinion pieces, ranging from medical journals to national newspapers to local community weeklies. Spend some time writing a patient's story and your perspective or reflections about it. Identify your target audience and then submit your work to the appropriate publication or media outlet.[21]

3. Social Media Campaigns

Social media is a powerful means to broadcast information to large audiences (see Box 8-3). Whether in the form of a YouTube video clip, Tweet, or Facebook post, social media messages can educate, help build public support, and reach decision makers. Many elected officials, for example, interact with constituents through their personal Twitter accounts. If your message goes viral, it can become a story in and of itself. Regardless of the platform, there are several ways to maximize a message's impact.

4. Lobbying Public Officials

For some issues, elected officials and their staff can play very important roles (see Box 8-4). Elected officials are sensitive to the concerns of their constituents. Engaging them is an opportunity to tell them about the problems in the community you serve. Many of your patients may never meet with a legislator, so tell your patients' stories on their behalf. While there are many ways to communicate with elected officials, such as signing a petition or writing a letter, typically the more personal and time intensive the format, the more influential it will be. For example, a hand-written letter has more weight than an email. Approach communication with the intention of building an ongoing relationship with the official and their staff. Do not be disappointed if you are unable to meet with the legislator directly; a meeting with the legislator's staff member may have a big impact.

Box 8-3. Helpful Hints for Conducting a Social Media Campaign

- Plan carefully. Going "viral" usually relies on a strategy that includes coordinating with multiple people to propagate the message.
- Plan for how to respond to negative reactions.
- Consider timing. The message has to go public when people are looking. There are certain times of the day and/or days of the week when your target audience is most likely to see it. To learn more about timing social media, consider looking at business sites such as Social Media Today (http://socialmediatoday.com).
- Make your message "sticky." In social media, attention spans are very short. The message should be relevant (e.g., tied to a breaking story). Attach a picture whenever possible.
- Be social. Engage with the people who respond to your Tweet or other messages and respond back.
- Include an "ask." Combine your argument for change with an action step to bring about that change, e.g., sign a petition, call a legislator, and vote in an election.
- Measure your impact. There are various online tools, such as SproutSocial (www.sproutsocial.com/social-measurement) and Sysomos (www.sysomos.com), to estimate your "impressions" to gauge the social media campaign's impact.

Box 8-4. Helpful Hints for Lobbying a Public Official

- Contact the office of your elected official and schedule an in-person meeting.
- Prior to the meeting, research the official's background on the matter looking for a connection to the issue you would like to discuss. Plan your discussion points, including why it is important to you and the official's constituents. Include an "ask," or something that the official can do to help you meet your advocacy goals. Prepare a one- to two-page "leave behind" document that includes your talking points and your contact information.
- At the appointment, express your concerns, share your "leave behind" document, and offer yourself as a resource on the matter for future inquiries.
- After the meeting, send a thank you letter including information on how they can reach you for further follow up on the matter.

5. Organizational Involvement

While individual health professionals can have a significant impact through community advocacy activities, professional or other advocacy organizations may provide additional sustainability and influence. For example, influential organizations are regarded as stakeholders and are often invited by decision makers to shape policy. Joining a professional society aligned with your concerns and goals is an easy first step; serving on committees or in leadership roles enables you to have a greater voice in the organization's direction. Another option is to join the board of directors of a community-based organization that is focused on an issue you care about, such as food, housing, or health-care policy. The key is to choose an organization whose work is congruent with your values and goals.

HEALTH PROFESSIONAL ADVOCACY TRAINING

Advocacy is an essential skill for any health-care professional working with vulnerable populations. Many professional organizations have called for curricular reform that includes advocacy training.[23-26] This training must be geared toward a variety of audiences, including undergraduate and graduate-level students and even practicing professionals, all of who need opportunities to develop advocacy skills.[26]

Increasingly, health professional training schools offer advocacy training opportunities for students and graduates.[27-33] As one example, the University of California, San Francisco, has a novel interprofessional program that incorporates learners from the Schools of Pharmacy, Nursing, Dentistry, and Medicine and the Graduate Division, and includes dedicated competencies related to leadership and advocacy (http://meded.ucsf.edu/hs).

Multiple opportunities exist for self-directed learning in the advocacy domain. Many professional organizations provide on line advocacy training, including the American Academy of Pediatrics training modules on subjects including Overview of the Legislative Process, Working in Partnerships, Working with Decision-Makers, and Advocacy Communication (http://www2.aap.org/commpeds/CPTI/training-modules.cfm). The National Institute for Children's Health Quality also offers an on line Advocacy Training Course, an Advocacy Guide, and an Advocacy Toolbox, which together focused on training health-care professionals to become advocates for change in their communities (http://www.nichq.org/advocacy/modules.html).

CONCLUSION

Advocacy—whether at individual, institutional, or population levels—is an important part of a health-care professional's responsibilities. In vulnerable communities particularly, where nonmedical factors powerfully impact health status and may limit wellness opportunities, advocacy is an important component of professional activity. Health-care professionals serving vulnerable populations can promote healthy communities by working across the advocacy spectrum.

- Many health professional activities can be considered "advocacy," ranging from direct patient care activities to institutional and community-level work.
- Vulnerable populations may experience a particular benefit from community-level advocacy efforts because the influence of social and environmental circumstances on health can be dramatic and the ability to change these circumstances depends on social structures and power.
- Advocacy targets include legislative, regulatory, institutional, and community levels.
- Various advocacy tools can be used for influence and communication. Choosing the most appropriate tool depends on the advocacy topic and project goals, and the advocate's availability.
- Multiple organizations offer training to improve advocacy skills for health professionals.

A common problem for health-care professionals is determining where to start in advocacy and how to incorporate advocacy into their busy schedules. Here is a series of steps that can help get you started.

1. **Ask a question.**
   Every day hundreds of issues are revealed during routine patient encounters. The first step is to ask questions that may illuminate the underlying issues for that patient. For your obese patient: Where does he eat? What kinds of affordable food choices are realistically available? Does he exercise? Is his neighborhood safe enough to encourage him to go out walking on a daily basis?
2. **Review the medical evidence.**
   If there is scant evidence, think of how you might document a concern or study an intervention.
3. **Collect stories.**
   The heart of health-care advocacy is the patient story. A patient's story can make an abstract issue concrete by creating a human connection with the audience. However, patient stories are easily forgotten in a busy day. After a memorable patient encounter, write down a few details of the story, even if it is only a few sentences in an email to yourself. You may also find a pattern that

emerges from different patients with the same illness; or you may identify a rise in asthma rates or neighborhood environmental exposures.

4. **Engage with community groups.**
   The issues that your patients face are not likely to be new or suffered in isolation and you are unlikely to be the only person interested. Find out how the community is (or is not) addressing the issues and get to know other advocates involved. They may be some of the best people to help you find resources for your patients. By sharing networks, skills, and energy, partnering will increase the likelihood of accomplishing shared goals. If you identify a like-minded group, consider serving the organization in a volunteer capacity.
5. **Get involved with a professional society.**
   It is likely that others in your profession have patients with similar concerns and would join you in your advocacy efforts. Getting involved with and even taking a leadership role in a professional society is an important way to influence practice in your profession, leverage the influence of your profession on a particular issue, and to network with like-minded individuals.
6. **Vote.**
   As a primary means by which citizens shape the direction of a democratic society, voting is advocacy in the most basic sense. Health professionals' unique insights into the health needs of communities are expressed by voting. Learn the issues in your community and then vote. Encourage your colleagues and patients to vote, too.[30]

DISCUSSION QUESTIONS

1. What forms of advocacy have you utilized? What were the challenges you faced getting involved in those activities and how did you surpass them?
2. What do you or your colleagues see as personal and/or professional obstacles to advocating for your patients?
3. Think about a patient with social vulnerabilities. What one activity discussed in this chapter could help this patient? What could you commit to doing on his or her behalf?

RESOURCES

Letters to the Editor

http://www.ucsusa.org/action/writing-an-lte.html

http://www.washingtonpost.com/blogs/ask-the-post/post/how-to-send-a-letter-to-the-editor/2011/11/17/gIQAoi7IlN_blog.html

Public Medical Writing

http://www.theopedproject.org

http://newsoffice.duke.edu/duke_resources/oped

http://www.healthitweek.org/toolkit_opEd_Sample.asp

Aronson L. How do we tell the stories of medicine? The Lancet. 2014;383(9927):1456-1457.

Lobbying

http://www.whpa.org/ppe_advocacy_guide.pdf

http://www.sophe.org/ChronicDiseasePolicy/Full_Guide.pdf

Farrer L, Marinetti C, Cavaco YK, Costongs C. Advocacy for health equity: A synthesis review. Milbank Q 2015;93:392-437.

Social Media Campaigns

http://www.thecommunityguide.org/healthcommunication/index.html

http://www.cdc.gov/socialmedia/tools/guidelines/pdf/socialmediatoolkit_bm.pdf

http://www.clinicalpsychiatrynews.com/home/article/video-the-don-ts-of-social-media-for-physicians/32a127e332d706f8f-726cb26172ea775.html

Online Advocacy Training

American Academy of Pediatrics: http://www2.aap.org/commpeds/CPTI/training-modules.cfm

Society of Teachers in Family Medicine: http://www.stfm.org/OnlineEd/AdvocacyCourse

Education Campaigns

http://www.uk.sagepub.com/upm-data/36852_Corcoran_Ch_01.pdf

Voting

http://www.lwv.org

RxDemocracy.org

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PART 2

Practice

CHAPTERS

9 Practical Strategies in Addressing Social Determinants of Health in Clinical Settings

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Chapter 9

Practical Strategies in Addressing Social Determinants of Health in Clinical Settings

Laura Gottlieb, MD, Rishi Manchanda, MD, and Megan Sandel, MD

Objectives

- Describe clinical tools for social, environmental, and legal needs screening.
- Describe clinical tools for social, environmental, and legal needs referral and tracking.
- Describe workforce training needs for addressing social determinants of health.
- Describe how clinic-based interventions to address social determinants of health can both link with and reinforce population-level interventions.

Veronica is a 40-year-old woman with asthma. She visited three emergency rooms (ER) in 1 month. Following the third ER visit, she was referred to a primary care clinic where a medical assistant noted that she lived in an area endemic for unhealthy housing. Veronica then was screened for associated housing risks. Veronica lived in a damp, moldy home. With that information, the MD correctly diagnosed her with a housing-related illness. He treated her with medications and enrolled her in a healthy housing program. Veronica and her home got better.

INTRODUCTION

It has long been recognized that social forces—poverty, class, gender, racism, war, and social policies—have a profound effect on disease: on who gets ill, the spread, and course of illness. Rudolf Virchow, a German physician, is credited with not only being the founder of pathology and cellular biology but also the father of social medicine. He advanced the idea that disease is not purely biological, but can be caused, spread, and exacerbated by social factors. To combat disease, Virchow suggested scientific medicine should be combined with population health, public health, and politics. In 1848, for example, he concluded that the cause of a typhus outbreak was largely due to wretched living conditions and that such an epidemic could be very simply prevented through "education, with its daughters, liberty and prosperity …." With these insights, Virchow and others committed to social justice brought about stunning improvements in health in the 19th century, long before the advent of antibiotics and other miracles of modern medicine, through social policies addressing poverty, improving public sanitation, as well as working and housing conditions.

Contemporary social medicine advocates still recognize inequality as a potent factor underlying disease and have been very influential globally. Tackling the HIV pandemic, for example, has required not only understanding the biology of the virus but also supporting the rights of the poor, women, sex workers, children, drug addicts, and sexual minorities and challenging systems that put treatments out of the financial reach of patients.

In the United States, Virchow's insights have not been widely incorporated into social policies or medical practice. Currently, the US programs created to address social conditions that undermine health are associated with the safety net and are often reviled as "handouts." Issues such as poor housing conditions or food insecurity, which arguably would be more effectively addressed in the arena of public

Table 9-1. Three Intervention Levels on the Social Determinants of Health for the Health-Care Sector

Target	Patients	Institutional Populations	Community
Goals	Health-care organization (HCO) applies SDOH to interventions directed toward individuals	HCO applies SDOH data to direct intervention toward patient and employee populations	HCO influences policy debates or other community change processes
Potential Levers	• Adjust individual disease risk according to known social determinant risks • Co-locate medical and public health/other government programs • Improve referrals to off-site partners	• Report SDOH, health status, and utilization data on institutional population groups • Apply social determinants data to institutional policies and practices • Improve systems and interventions to address social/environmental factors for institutional populations	• Ensure data systems coordinate with relevant government, policy, or advocacy organizations. • Use aggregated data to influence policy decision making.
Intervention Examples	• Utilize medical assistants to refer food insecure patients to food benefits programs • Provide legal services through medical–legal partnerships	• Provide on-site farmer's markets • Offer physical activity subsidies or programs for members • Include utility protection letter designed by medical–legal partnerships in electronic health records • Offer living wages to all employees	• Lobby for increased cigarette taxes • Promote healthier food benefits packages • Advocate for healthy streets redesign

From Gottlieb L, Sandel M, Adler NE. Collecting and applying data on social determinants of health in health care settings. JAMA Intern Med 2013:173(11):1017-1020.

policy, present themselves as powerful issues undermining the health of patients. In the absence of an integrated social approach to health, clinicians struggle to care for patients suffering from the ill effects of their social vulnerabilities.

Advocating for patients' social and legal needs, whether in the context of clinical encounters, clinical systems, or broader political contexts, requires specific training and tools (see Chapter 8, Advocacy). Examples of patient-, institutional-, and community-level interventions addressing social and legal determinants of health are provided in Table 9-1.

In this chapter, we focus on practical, clinic-based strategies to address social determinants of health at the patient and clinical system levels within the US health-care system. These strategies require both redesigning clinical systems and training the health-care workforce.

SOCIAL DETERMINANTS OF HEALTH IN CLINICAL SETTINGS

In 2012, the "blindside" of US health care was revealed by a nationwide survey of physicians assessing providers' capacity to address patients' social and legal needs. The survey found that 9 of every 10 clinicians working in safety net settings believe that social factors strongly contribute to health-care outcomes, but 80% report lacking the capacity to address these factors.[1] The gap between health providers' awareness of social needs and capacity to address them contributes to delays in diagnoses, less effective, inefficient (and therefore costly) health-care delivery and utilization, health disparities, patient dissatisfaction, and clinician burnout.[2]

Despite the pervasiveness of social need and its impacts on both child and adult health, patients' social, environmental, and legal needs often remain unaddressed in clinical encounters. Addressing these needs, however, may bring significant health benefits. Connecting food insecure patients and families to community food resources and food stamps, for example, may bring about long-term improvements in individual and community health. Studies have demonstrated the association of food insecurity, for instance, with increased HIV risk behaviors and, separately, increased hypoglycemia-related hospital admissions at the end of the month due to the exhaustion of food budgets.[3,4]

Socioeconomic indicators can also enhance the utility of specific clinical screening recommendations. Fiscella et al incorporated patient income into 10-year Framingham Risk Score calculations, and found that doing so better identified patients at risk of developing cardiovascular disease than did traditional calculators.[5] Furthermore, adjusting for education improves the accuracy of the Mini-Mental State Examination in predicting disease likelihood.[6] As knowledge about health impacts of interventions to address social and legal determinants grows, both the health-care quality and long-term financial benefits of adopting these interventions will become increasingly persuasive.

CLINICAL SYSTEMS REDESIGN

Many forces in the US system of health—from the historically separate development of our public health system and our medical schools to more recent health-care reimbursement systems that reward volume of services over value for money spent[7]—have stymied addressing social determinants of health both in clinic settings and the health-care system more generally.[8] The passage and implementation of the 2010 Patient Protection and Affordable Care Act (ACA) has led a number of payers in the public and private sector to explore ways of shifting from volume-based to value-based payment models that support continuity and coordination of care. Providers are being asked to reorganize and redesign the way they deliver care using models such as the Patient-Centered Medical Home (PCMH). Since social, legal, and environmental factors are major determinants of health outcomes, particularly among vulnerable populations, redesign efforts that seek to optimize value in clinical systems must incorporate methods to address relevant social determinants.[8]

Clinic system redesign is the systematic process of analyzing current clinical operations and planning new operational systems to improve the efficiency, quality, and effectiveness of patient care.[9,10] In US primary care settings, the components of clinic system redesign have been widely spread through financial incentives offered by a number of state and commercial payers.[11,12] Some categories of redesign that garner enhanced reimbursement are related to patient-centered access; team-based care; population health management; care management and support; care coordination; and care transitions.[13] Methods to address upstream social, environmental, and legal needs can align with and support clinic system redesign efforts, helping clinic systems meet new standards such as those established for PCMH and other models of coordinated care delivery (e.g., the patient-level Ambulatory Intensive Care Unit model or the system-level Accountable Care Organization model).

A typical patient-centered clinic workflow can be a helpful framework to consider ways to understand and address social determinants in clinical settings that serve vulnerable populations. Specific clinic functions in a typical workflow include screening, triage, evaluation and management, documentation; referrals, and follow-up. Clinical tools that address social determinants of health often seek to enhance one or more of these ambulatory patient-care functions.

SCREENING FOR SOCIAL DETERMINANTS OF HEALTH

There are two key operational questions to answer when considering screening for social determinants of health in clinical settings: "Which social determinants of health should we screen for?" and "How will we screen for these social determinants of health?"

Choosing which social determinants of health to screen for in a clinic setting can be challenging. To balance the need for useful, locally relevant social factor data that can inform patient care with the need for useful population-level data that can aid public health and research efforts, policymakers and clinical providers are encouraged to capture "Core" (foundational) measures and "Custom" (flexible) measures related to social determinants of health.

"Core" measures collected by all clinical sites

Clinics should first capture "Core" social needs and characteristics relevant to the care of most, if not all, vulnerable patient populations receiving care in the system. We recommend capturing "Core" socio-demographic domains described by a committee of the Institute of Medicine in 2014 (Box 9-1).[14]

"Custom" measures, clinic and population specific

Clinics should then take steps to capture "custom" measures tailored to community and clinic priorities that reflect local social determinants of health. These might include such issues as screening for risk of dropping out of school in adolescents, pesticide exposure in agricultural communities, history of political violence in refugees, or food insecurity in low-income, urban populations.

Choose validated screening tools when possible

A variety of screening tools to identify social, legal, and environmental needs are currently in use in clinical practice. They include validated, published tools developed by researchers as well as unpublished, "home-grown" surveys and questionnaires developed by frontline clinic staff eager to respond to perceived unmet social needs. Some tools are specific to a particular social factor such as food insecurity or occupational exposures and often reflect clinic projects supported by external funders with specific interests in a particular social need.[15-17] Other tools are more comprehensive, covering several social, legal, or

Box 9-1. "Core" Socio-demographic Domains

- Race/ethnicity
- Country of origin/US born or non-US born
- Education
- Employment status
- Financial resource strain: food and housing insecurity
- Sexual orientation

environmental domains (see www.HelpSteps.com).[18] A compilation of social screening tools is currently maintained by an online learning collaborative organized by HealthBegins (http://healthbegins.ning.com/page/social-screening-tool). The "Core Competency" at the end of this chapter includes specific items and references to several social screening tools used around the country.

Based on population needs and clinic priorities, many more topics could be considered, including domains related to social isolation, stress, violence, and literacy. The scientific validity of individual questions varies. Some questions such as those related to housing and food security have been well studied, but wide-scale adoption of comprehensive screening tools could be strengthened by improved validity testing to make sure that these questions maximize accurate disclosure on relevant, sensitive social and legal issues.

To improve institutional "buy-in" and the diversity of input, the screening selection process for "custom" measures should be participatory and involve representatives from different clinic and community stakeholder groups, including patients, clinicians, health information technology staff, billing/coding staff, social workers, care managers, enabling service staff, outreach/community health workers (CHWs), and community-based social service providers and advocates.

Community-specific social needs

After identifying their community catchment area, clinics are encouraged to contact local hospitals, public health departments, county agencies, nonprofit social service providers, advocacy organizations, and/or academic research institutions to obtain data and reports such as Community Health Needs Assessments that reflect local, population-specific unmet social needs. Clinics can also use web-based survey software, key informant interviews, focus groups, and other methods to collect primary data from community partners.

Community-specific resources

Clinics often choose not to screen for unmet social needs due to a lack of awareness of local community resources that can address them. In contacting local partners to identify unmet social needs as indicated earlier, clinics can also generate and update community-specific social resource maps. Clinics should strive to select "Custom" social screening measures for which local corresponding resources have been identified.

Clinic priorities

Patients with health problems or costly utilization patterns that are caused or exacerbated by unmet social needs can be a challenge to clinics that are striving both to improve care for individuals and populations and decrease costs. The selection of "Custom" measures for social needs screening should reflect the clinic's need to improve care and outcomes for specific vulnerable and challenging patient populations.

Optimize use of the Care Team

As clinics shift to team-based care models, methods that solely rely on the clinician to screen for core and custom measures related to social determinants of health are not recommended. Instead, consider redesigning the workflow of social screening to distribute the collection of core and/or custom social measures among other care team members and across different steps in the patient experience. These steps include pre-visit; patient registration/check-in; waiting room; vitals; in exam room/pre-clinician encounter; clinician encounter; post-encounter/in-room; lab; pharmacy; care coordinator, and scheduling follow-up.

Explore Electronic Health Record (EHR) and non-EHR–based tools

When possible, clinics should work with electronic health record (EHR) vendors, clinical EHR champions, in-house information officers, and other information technology staff to build social screening items into their EHR. Alternatively, other tools—such as self-directed and/or staff-assisted surveys via in-person or phone-based interviews or secure SMS, email systems, kiosks, or other standalone web-based software-as-a-service platforms—can be used to capture key data on unmet social needs (see HelpSteps.org; Healthify.us).

Triage

The degree to which screening tools are successfully integrated in clinical practice depends on several factors, including buy-in from clinic and community stakeholders as well as the clinic's ability to triage or sort patients to appropriate resources using these screening tools. Appropriate triage of unmet social needs identified in clinic settings should align with other practice-based triage processes. These should ensure that the clinic's written, posted triage policy is updated to include social, legal, and environmental needs and is developed and signed off by relevant clinic leaders, including medical, nursing, social work, quality, and legal supervisors. This policy should include protocols for "warm handoffs" between clinic staff when possible, as well as random chart reviews and other quality assurance mechanisms.

Clinic staff will also need to incorporate the triage of unmet social needs into existing patient care workflows or to create a parallel triage process that is independent of the patient–clinician encounter. Depending on the social need, patient population, and clinic priorities, clinics may

choose to have a clinician involved in the triage process to review any health-related social needs. This can be facilitated through several mechanisms, including pre-visit chart reviews; team huddles; or the integration of social workers, health educators, and/or CHWs into the care team and patient visit. Alternatively, tools such as EHRs with decision-support software can automate social needs triage, linking patients to community resources without the need for clinician discussion through printed handouts, SMS, phone calls, or email. The use of computerized order entry, standing orders, and decision support software can improve the efficiency of social needs triage.[19]

EVALUATION AND MANAGEMENT

While some clinics may decide to create a triage process that does not require that clinicians directly address social needs, it is important for clinicians and care team members to understand the ways in which social, environmental, or legal needs can have a direct impact on patient health and medical decision making. This understanding can inform and improve evaluation, diagnosis, and the effectiveness of treatment plans.

As clinically relevant information related to social determinants of health continues to expand, care team members, including clinicians, will have greater opportunities and professional obligations to incorporate this information directly into their evaluation of patients' presenting complaints and symptoms. As part of continuous quality improvement (QI) efforts, health-care professionals should avail themselves of emerging tools, continuing educational opportunities, and practice-based learning collaboratives to stay updated about the latest evidence regarding the complex interplay between social determinants and patient and community health.

Clinic system operational efficiencies also can improve management and treatment of health-related social needs. For example, clinicians involved in the medical–legal partnership at Boston Medical Center (BMC) routinely use templates to quickly generate letters for patients who are facing utility shut-offs (see Case Study), need supporting documentation for disability applications, require special education accommodations at school, or need to establish guardianship to facilitate caregiving.

DOCUMENTATION—CODING/CHARTING/BILLING

When health-related social needs are identified for individual patients, it is essential that clinicians and other care team members document social needs as indicated in the History of Present Illness section of their notes; the "Social History" section; in their assessment and treatment plans when relevant; and finally, in billing documentation, using ICD-9 (and soon ICD-10) codes.

Appropriate and accurate coding of health-related social needs addressed during an encounter using ICD codes yields better data for clinic-level and public health planning purposes and may also improve workload capture and clinic reimbursement rates by demonstrating the necessity of current procedural terminology and evaluation and management codes associated with the care of patients with complex bio-psycho-social needs.

REFERRALS AND FOLLOW-UP

Computer- or cloud-based databases will improve the accuracy, speed, portability, and sharing of resource information among clinic providers, community stakeholders, and patients. While resource databases typically include information on local social service agencies or providers, clinics should include resources that promote social connectedness and support (e.g., faith-based organizations or social clubs) as well as organizations that promote civic engagement, community organizing, and advocacy. A growing number of these electronic tools are now available to support clinics seeking to refer patients with social needs to community-based resources (Table 9-2).

Referral tracking

In addition to streamlining the process of finding and connecting patients to community resources, clinic systems can enable patient- and population-level tracking of community resource referrals. This facilitates performance measurement and QI efforts and aligns with PCMH standards and other clinic redesign efforts. Electronic referral systems integrated into the EHR can be a source of information for performance measurement. For instance, providers from the San Francisco General Hospital and Trauma Center can refer clients directly to the Financial Fitness Clinic for budgeting or tax assistance services and referrals can be tracked across the hospital. External electronic tools such as Healthify, One Degree, and others (see Table 9-2) include data tracking functions that can help health-care institutions better collect and track the social needs of their populations.

Clinic–community engagement

Resource mapping and referral models, such as the "Community Health Detailing" model developed in Los Angeles by HealthBegins (Box 9-2) or the HealtheRx approach in Chicago, foster a participatory, community-driven approach that leverages the knowledge and expertise of local residents to address social determinants of health and improve the capacity of clinics to help patients with social needs. These models use local residents to create and maintain databanks of community resources information.

Table 9-2. Electronic Social Determinants of Health Screening and/or Referral Platforms

Program	Website	Summary
One Degree	1deg.org	Screening and web-based algorithms to help any user find available community resources. Data tracking available
Purple Binder	http://purplebinder.com	Screening and web-based algorithms to help any user find available community resources. Includes texting options for patient follow-up. Data tracking available
HealtheRx	http://healtherx.org/	Community health information specialists and web-based platform to help any user find available community resources. Data tracking available
HelpSteps	https://www.helpsteps.com	Screening and web-based algorithms available to help any user locate available community resources.
Aunt Bertha	http://www.auntbertha.com	Web-based algorithms available to help any user locate available community resources.
211	211.org	Web- and phone-based databank of available community resources available to any user
Health Leads	https://Healthleadsusa.org	Non–web-based electronic algorithms to help users find available community resources. Use limited to program staff. Data tracking available
Healthify	Healthify.us	Non–web-based electronic screening and algorithms to help users find available community resources. Includes texting options for patient follow-up. Data tracking available

HealtheRx enlists community health information specialists to staff phone and web connection support.

Privacy/Security

Referral methods that link and track patients must be Health Insurance Portability & Accountability Act (HIPAA) compliant and must maintain patient privacy. Data use sharing agreements, business associate agreements, and other written policies must be considered for clinics seeking to share data with community partners or third-party vendors.

Clinic redesign efforts to address social, legal, and environmental factors are not complete unless they support continuity of care and routine follow-up. Clinics must also clearly assign responsibility for follow-up of specific tasks to individual care team members.

Box 9-2. HealthBegins "Community Health Detailing" Model

Goals

- Increase community residents' knowledge and efficacy to improve local social determinants of health.
- Improve care for patients with health-related social needs.

How It Works—Four Key Components

- Participatory, popular-education–based 3-month curriculum in which community residents learn about social determinants of health and local health-care delivery systems.
- Participatory resource mapping, where learners identify and map local community resources to improve social determinants of health.
- Online, searchable, geographic database, which allows health-care providers to find community resources (mapped by community members) for patients with social needs.
- "Detailing," in which community residents visit and educate health-care professionals about local social determinants of health and available community resources in order to streamline care for patients with social needs.

INCREASE HEALTH-CARE WORKFORCE TRAINING AND CAPACITY TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

New functions will need to be integrated into the health-care team's roles if social needs are to be successfully addressed within the clinical arena. Team members' responsibilities will need to align with their skills to enable health-care systems to address a wider range of health determinants. Adoption of routine social and legal needs screening will require clinical champions who support the development and integration of social determinant screening and intervention as a critical component of health-care delivery. Medical legal partnerships (MLP), for instance, typically support both a legal services provider and a medical clinical champion. The MLP clinical champion facilitates the integration of legal screening into routine clinical care processes, and leads to QI, teaching, and research efforts. These clinical champions, whether

for MLP or other social determinants programs embedded in health-care settings, have been referred to by some as Upstreamists.[8] Armed with knowledge and skills related to the myriad intersections of public health and clinical medicine, Upstreamists bring a social determinants of health lens into clinic system transformations.

Beyond medical champions, however, health-care teams will need to adapt other specific team roles to ensure that members have expertise in asking about and managing relevant social needs, and that they are able to meet the demand for services and relevant follow-up in any particular area. Though electronic platforms help meet this demand by maximizing clinical efficiency as described earlier, trained staff are still essential. For instance, though most social service needs are traditionally referred to social workers, reimbursement barriers, social worker shortages, and issues of geographical and racial/ethnic and linguistic diversity may limit their capacity in many underserved settings.[20] Some hospitals and clinics have enhanced the capacity of social workers to operate at the top of their training by also incorporating paraprofessionals or volunteers to help triage and manage social needs. Health Leads, a nonprofit operating in six cities across the United States, uses trained college student volunteers to help manage patient social needs (healthleadsusa.org). CHWs can play important roles in facilitating team-based care that includes social and/or legal needs.[21,22] Some states—including New Mexico and Minnesota—have used state Medicaid funding to support CHWs and other nontraditional providers.[23]

The technological tools described earlier can help clinical staff efficiently manage social needs. For instance, once patients with food insecurity are successfully identified, electronic systems can automatically print Supplemental Nutrition Assistance Program (SNAP) applications and maps showing food pantries close to patients' homes. Staff with related expertise can then help families complete benefits applications and spend more time on complex issues. The Health Leads program, for instance, combines trained student volunteers with a sophisticated technology platform that identifies relevant community resources for patients. The volunteer advocates help patients complete forms, schedule appointments, and follow-up with social service agencies identified by the computerized algorithms. Tools that promote collaborative management of tasks among care team members, rather than tools that limit care management to one team member, are especially useful for patients with multiple social, legal, and environmental needs. Clinic performance measures for care teams as a whole and for specific service lines (e.g., clinicians, social workers, and care managers) can reinforce team accountability and quality of routine follow-up for patients with unmet social needs.

Families with complex legal needs related to social challenges may be referred to on- or off-site legal services for additional professional services. Articulating the legal provider's role in team-based clinical care, as well as in clinic transformation, is part of the work of the National Center for Medical Legal Partnerships (http://medical-legalpartnership.org). Legal staff can educate and supervise nonprofessional team members as well as be available for individual patient consultations and/or lead advocacy efforts at clinical and population levels. Mounting evidence shows that adding legal aid to the array of health-care services provided in underserved settings can improve patient health status[24] and be cost-effective.[25]

Existing models for addressing social needs such as those described earlier require distinct resources and personnel depending on the type of need. Generally, the more resource and training intensive an intervention, the higher its potential health impact, but the fewer the patients who may need it. For example, a volunteer-based community resource linkage program such as Health Leads incorporated into a clinical setting requires relatively few resources—primarily training and supervising volunteers—and can serve a significant number of patients with basic social resource needs. In contrast, a medical–legal partnership, which requires trained legal staff, may have greater potential to impact complex social determinants, but typically is needed by a smaller number of patients.

Since no single intervention can achieve a balance of breadth and depth in meeting the full spectrum of patients' social needs, a tiered model is most likely to efficiently maximize impact and scope (Figure 9-1). This tiered model integrates lower intensity/higher capacity interventions (e.g., automated referrals or nonprofessional consultations) that serve a wide spectrum of need and high numbers of patients, with higher intensity/limited capacity activities (e.g., social work or legal consultations) that will likely have significant impact for individuals, but serve fewer patients. In such a model, less expensive personnel address a broader range of social needs by participating in lower-tier interventions (e.g., providing utility shut-off letters) or using algorithms to refer more complex needs to professionals. Each clinical site can adopt context-specific interventions, selecting different staffing and intervention combinations targeted to their population's social needs and available resources. To maximize efficiency, the tiered workforce model will need to be built on a system-wide electronic screening and referral platform.

Finally, supporting staff and clinical champions in this area will require dedicated learning collaboratives to share and spread best practices, networks for peer support and mentorship, and opportunities for specialized training. For example, HealthBegins (healthbegins.org), a health

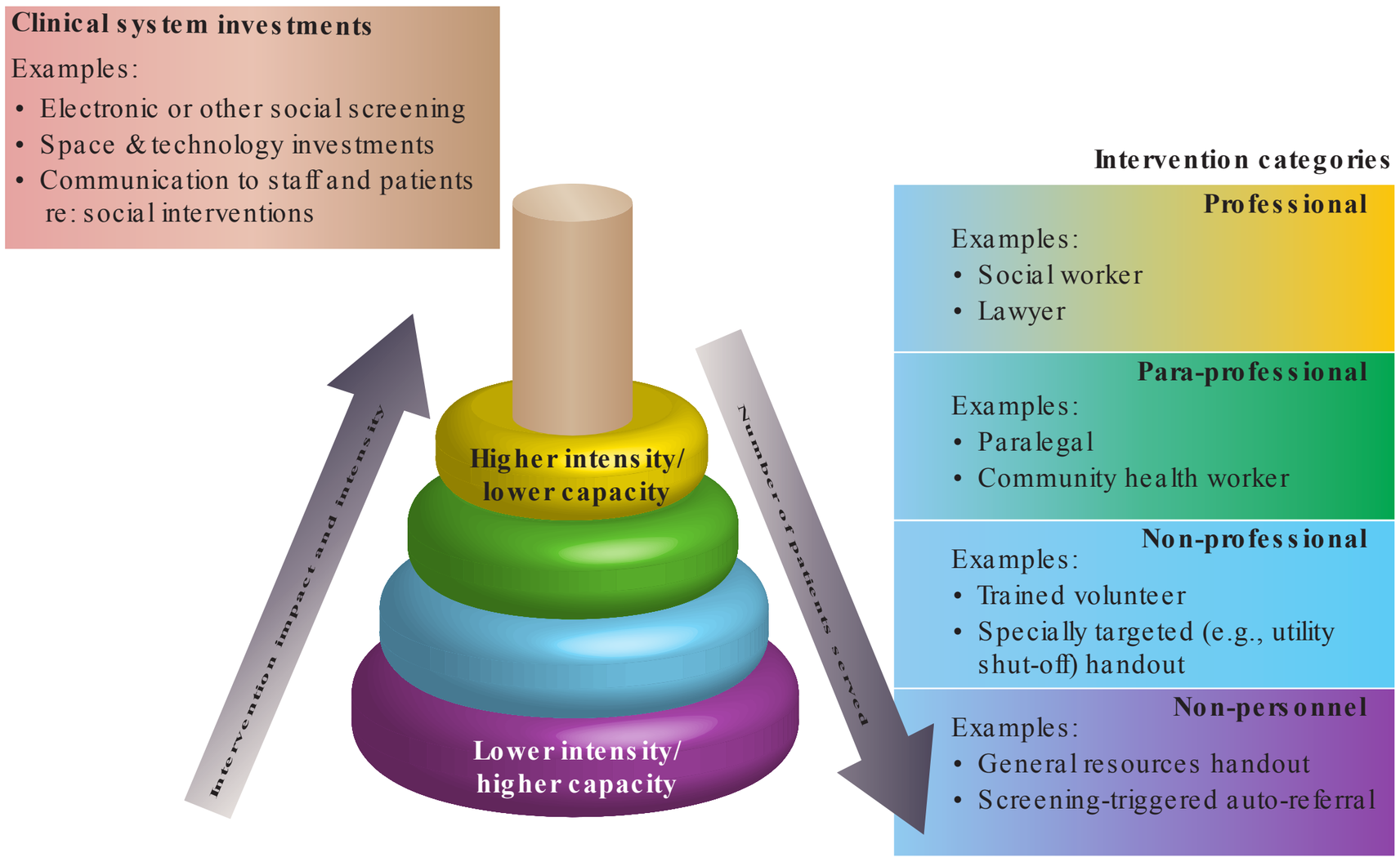


Figure 9-1. Workforce model for clinical social determinants of health interventions.

innovation incubator focused on vulnerable populations, has developed an online network and training platform for clinicians and partners interested in addressing social determinants of health in clinical settings (Box 9-3). The initiative, Practical Playbook: Public Health and Primary Care Together, includes a three-part web-based learning guide for public health and primary care partnerships (https://practicalplaybook.org). Additional communication training resources, such as those offered by the American Academy on Communication in Healthcare (http://www.aachonline.org), can be adapted to support provider engagement related to social determinants of health interventions.

Box 9-3. Common Pitfalls

Incorporating Social Determinants of Health Interventions in Clinical Settings

- Systematic screening for social, legal, and environmental health determinants is rarely performed using validated instruments.
- The entire health-care team is not trained on best screening practices or provided with up-to-date community referral resources.
- Community resources that provide educational, social, environmental, and legal support to patients are not identified, organized, and updated in a manner to facilitate easy referrals.
- Social, legal, educational, and environmental issues are not integrated into medical decision making.
- Staff is rarely held accountable for follow-up of social, legal, and environmental needs and referrals.
- Social and legal needs data collected in clinical settings are not applied to population health efforts or shared with other public health stakeholders.

FUNDING AND OTHER INCENTIVES

There are few explicit financial incentives for clinics to prioritize data collection and resource allocation focused on social determinants of health. Medicare and Medicaid EHR Incentive Programs are a major driver for EHR adoption nationwide, but Stage 1 and Stage 2 meaningful EHR use guidelines from the Office of the National Coordinator have not focused on social determinants of health. Stage 3 guidelines will include more on population-based care, including coordination with community-based resources.[26] Moreover, the 2014 PCMH accreditation standards from the National Center for Quality Insurance (NCQA) mention social determinants of health and are aimed to align with Medicare/Medicaid meaningful use guidelines, which include population management and coordination with community-based resources. Developing systematized social needs screening and resource interventions can help clinics achieve PCMH accreditation under the 2014 standards and thus PCMH-linked incentives from state and commercial payers. Furthermore, several states are already using Medicaid coverage to support nonmedical services. For instance, Rhode Island's lead abatement program[27] and Massachusetts'

Pediatric Asthma Pilot[28] show how Medicaid benefits can be used for programs that provide remediation for environmental threats (such as lead, mold, and rodents) to children's health.

Other financial incentives may emerge in conjunction with ICD-10 adoption in the United States ICD-10 includes over 83 individual z-codes for health hazards related to socioeconomic and psychosocial factors. These include categories under education and literacy, employment and unemployment, and housing and economic circumstances (Table 9-3). As social determinants increasingly are incorporated into risk stratification algorithms, these codes will enable increased reimbursement for providers caring for patients with social vulnerabilities.

Changes in nonprofit hospital community benefit allocations also create financial incentives for nonprofit infrastructure and activities aimed at patient social needs. New internal revenue service reporting requirements will hold institutions accountable for conducting a community health needs assessment every 3 years to assess

Table 9-3. Excerpts from ICD-10: Z-codes

Code	Description
Z55.0	Illiteracy and low-level literacy
Z55.1	Schooling unavailable and unattainable
Z55.2	Failed school examinations
Z55.3	Underachievement in school
Z55.4	Educational maladjustment and discord with teachers and classmates
Z55.8	Other problems related to education and literacy
Z55.9	Problems related to education and literacy, unspecified
Z56.0	Unemployment, unspecified
Z56.1	Change of job
Z56.2	Threat of job loss
Z56.3	Stressful work schedule
Z56.4	Discord with boss and workmates
Z56.5	Uncongenial work environment
Z56.6	Other physical and mental strain related to work
Z56.81	Sexual harassment on the job
Z56.82	Military deployment status
Z56.89	Other problems related to employment
Z56.9	Unspecified problems related to employment
Z57.0	Occupational exposure to noise
Z57.1	Occupational exposure to radiation
Z57.2	Occupational exposure to dust
Z57.31	Occupational exposure to environmental tobacco smoke
Z57.39	Occupational exposure to other air contaminants
Z57.4	Occupational exposure to toxic agents in agriculture
Z57.5	Occupational exposure to toxic agents in other industries
Z57.6	Occupational exposure to extreme temperature
Z57.7	Occupational exposure to vibration
Z57.8	Occupational exposure to other risk factors
Z57.9	Occupational exposure to unspecified risk factor
Z59.0	Homelessness
Z59.1	Inadequate housing, including inadequate space, lack of heating, and unsatisfactory surroundings
Z59.2	Discord with neighbors, lodgers, and landlord
Z59.3	Problems related to living in residential institution
Z59.4	Lack of adequate food and safe drinking water
Z59.5	Extreme poverty
Z59.6	Low income
Z59.7	Insufficient social insurance and welfare support
Z59.8	Other problems related to housing and economic circumstances
Z59.9	Problem related to housing and economic circumstances, unspecified
Z60.0	Problems of adjustment to life-cycle transitions
Z60.2	Problems related to living alone
Z60.3	Acculturation difficulty
Z60.4	Social exclusion and rejection
Z60.5	Target of (perceived) adverse discrimination and persecution
Z60.8	Other problems related to social environment
Z60.9	Problem related to social environment, unspecified

Note: Z-codes are unacceptable as principal diagnoses, but describe circumstances which influence health and can specify diagnoses.

community needs and support community development activities that address the root causes of poor health.[29] Supporting social screening and community-based interventions to address social determinants of health could help hospitals meet these new requirements, enabling innovative mission alignment across any health-care institution.

HOW CLINIC-LEVEL INTERVENTIONS CAN LEAD TO POPULATION-LEVEL INTERVENTIONS: CASE STUDIES

UTILITY SHUT-OFF PROTECTIONS

Many states have legal protections to avoid utility service shut-offs for nonpayment to protect against potential health consequences of losing electricity for people dependent on medical devices such as nebulizers or respirators. To maintain service in these instances, a utility shut-off protection letter is mailed or faxed from a health-care provider to a utility company stating that the provider cares for a patient with a chronic illness and that the patient's medical treatment depends on utility service. Barriers to including shut-off protection letters in routine clinical care include provider time, training, and lack of clinical infrastructure to support these activities.

The medical–legal partnership at BMC, MLP | Boston, devised a letter meeting all legal requirements for utility companies to maintain service that is now integrated into the BMC EHR. The letter can be autopopulated with the patient's demographic information and documents that the patient has a chronic serious illness, which the provider can specify with patient's permission. The letter's inclusion in the EHR makes it possible for providers to complete it quickly during patient appointments. Because of the EHR integration and associated trainings to increase provider awareness of utility shut-off consequences, the number of protection letters written in the BMC Clinic increased substantially. Within 2 years, the clinic saw a 300% increase in the number of completed protection letters—from 193 in 2005–2006 to 676 in 2008–2009, during a time of stable clinical volume. The addition of the shut-off protection letter to the EHR streamlined the process for providers and decreased clinician time spent on providing protection letters—from an estimated 30 minutes down to 30 seconds.[30]

After noting the increase in utility shut-off letters, MLP Boston worked to submit joint testimony from a lawyer and pediatrician documenting the undue burden of quarterly documentation requirements, particularly in light of chronic disease prevalence among low-income residents. The Department of Public Utilities accepted this testimony and changed to biannual income and medical status documentation requirements. The department also allowed physician assistants and nurse practitioners to provide medical certification letters. These policy changes arose from direct clinical experiences and benefitted populations beyond those served by the clinical institution.

HOUSING QUALITY CASE STUDIES

The connection between substandard housing and health is well documented, particularly in the case of asthma. Local or state sanitary codes are designed to make these substandard housing conditions illegal, and require landlords to fix housing conditions. To enforce housing code, local health departments periodically inspect housing and, if indicated, cite the landlord and require remediation. The medical–legal partnership in Cincinnati, the Child Health-Law Partnership (HeLP) program, began to screen every child admitted with asthma for problems with housing and refer them to the medical–legal partnership for additional assistance to address identified housing concerns. Eventually the hospital inpatient unit created a QI project to ensure that every child admitted was screened, and that every positive response was referred to the local health department for code enforcement. The QI team noted patterns when they mapped the identified cases of poor housing quality. They discovered system-wide problems in housing developments owned by a single landlord and the legal services agency brought the landlord to court. The court ordered remediation of the entire development, not just individual units. This resulted in improved housing for the entire population and prevented further housing-triggered asthma attacks.

Similar programs in Seattle linking asthma patients with community health workers, who perform home visits, provide education and resources to improve ventilation and decrease triggers to asthma have shown significant reductions in both asthma exacerbations and the need for urgent health-care visits. In a partner project, low-income housing units were built to reduce asthma triggers. Together these clinical care and community interventions decrease costs and improve health. (For tools to implement similar programs in your community, see http://www.kingcounty.gov/healthservices/health/chronic/asthma/past/HH2.aspx.)

CONCLUSION

By regularly taking "social determinants of health vital signs," such as food, housing, and utilities security, among many others, health-care sites take not only the "pulse" of their patients but also the "pulse" of their communities. Validated instruments exist to identify unmet social needs; other tools engage the entire health-care team in

efforts to intervene on these social factors in the clinical setting, often in partnership with community-based organizations and social service agencies. Leveraging electronic medical records for screening, evaluation and management, documentation, and referral for unmet social needs is increasingly becoming a reality. Furthermore, case studies now exist to demonstrate how addressing social determinants of health at the patient- and clinic-level can improve clinical care, enhance patients' quality of life, and lead to policy opportunities to enhance population health.

- Health-care settings will need to identify core and custom measurement tools for unmet social needs, assign roles, and ensure training that best support interventions addressing social determinants of health for the population served.
- A wide variety of social determinants of health screening, triage, evaluation and management, referral, and follow-up tools exist.
- New funding models and incentive opportunities should promote wider dissemination of programs and practices that address the social needs of vulnerable populations in clinical settings.

Sample Social Screening Items

Social Determinant Domain	Screening Questions	Reference
Income	Does your family have enough money at the end of each month?	Keller et al 2008[31]
	Are you having problems receiving WIC, food stamps, daycare vouchers, medical card, or SSI?	Klein et al 2011[32]
	Do you ever have difficulty making ends meet at the end of the month?	Brcic et al 2010[15]
Food security/ hunger	• Have you ever been worried whether your food would run out before you got money to buy more? • Within the past year has the food you bought ever not lasted and you didn't have money to get more?	Hager et al 2010 [33]
	For each of these statements, tell me whether the statement is often, sometimes or never true for your household over the past 12 months. • I/we worried whether my/our food would run out before I/we got money to buy more • The food I/we bought just didn't last, and I/we didn't have money to get more. • I/we couldn't afford to buy balanced meals.	Economic Research Service 2012[34]
	Do you and your child have enough healthy food (including any special dietary needs) to eat every day?	Keller et al 2008[31]
	Do you worry that your food will run out before you get money or food stamps to get more?	Klein et al 2011[32]
	In the past month, was there any day when you or anyone in your family went hungry because you did not have enough money for food?	Kleinman et al 2007[35]
Housing costs	Do you have any concerns about not being able to pay your rent or mortgage?	Dacchille et al[36]
	Do you think you are at risk of becoming homeless?	Garg et al 2007[37]
	Do you have any concerns about your housing (safety, affordability, stability)?	Keller et al 2008[31]
	Are you being threatened with eviction or losing your home?	Klein et al 2011[32]
	Are you having any problems with housing (e.g., needing a new place to live or assistance locating housing—including nursing home placement/ assisted living)?	Bikson et al 2009[38]/Cook et al 1996[39]
Housing conditions	Are you having housing problems (overcrowding, roaches, rodents, utilities, mold, lead, etc.)?	Klein et al 2011[32]
	• Are you having problems with your housing? • Are you threatened with eviction or losing your home?	HealthBegins.org (http://healthbegins.ning.com/page/social-screening-tool)

	Do you have any concerns about poor housing conditions such as mice, mold, and cockroaches?	I-HELP/ NCMLP[36]
Personal safety	Do you have any concerns about your family's day-to-day safety or stability?	Keller et al 2008[31]
	"From speaking to families, I have learned that violence in the home is common and now I ask all families about violence in the home. Do you have any concerns about violence in your home?"	Dacchille et al[36]
	• Have you ever been in a relationship in which you were physically hurt or threatened by a partner? • In the past year, have you been afraid of a partner? • In the past year, have you thought of getting a court order for protection?	Dubowitz et al 2008[40]
	How often does your partner: • Physically hurt you? • Insult you or talk down to you? • Threaten you with harm? • Scream or curse at you?	Chen et al 2007[41]
	• Have you been hit, kicked, punched, or otherwise hurt by someone in the past year? If so, by whom? • Do you feel safe in your current relationship? • Is there a partner from a previous relationship who is making you feel unsafe now?	Feldhaus et al 1997[42]
	Do you feel that you and/or your children are unsafe in your relationships?	Klein et al 2011[32]
Education	What is the highest grade/year of school completed? (elementary, high school, college, graduate scales)	MacArthur Network SES
	Do you have a high school degree? If no, would you like help getting a GED?	Garg et al 2007[37]
Employment	Are you having any employment or career issues? Do you have a job? If not, would you like help with finding employment?	Bikson et al 2009[38]/Cook et al 1996[39] Garg et al 2007[37]
Neighborhood violence	• Do you feel safe walking alone during the day? • Do you feel safe walking alone during the night? • Do you feel afraid to let your children (grandchildren) play outside?	Johnson et al 2009[43]

RESOURCES

Robert Wood Johnson Foundation Health Care's Blind Side Report. http://www.rwjf.org/content/dam/farm/reports/surveys_and_polls/2011/rwjf71795

Positively Impacting Social Determinants of Health: How Safety Net Health Plans Lead the Way. 2014. http://www.communityplans.net/Portals/0/Fact%20Sheets/ACAP_Plans_and_Social_Determinants_of_Health.pdf

Health Begins: Healthbegins.org

National Center for Medical Legal Partnerships: Medical-legal-partnership.org

Regional Bay Area Help Desk Consortium: Bayareahelpdesks.org

Association of Academic Health Centers: Wherehealthbegins.org

Health Providers Against Poverty: Healthprovidersagainst-poverty.ca

DISCUSSION QUESTIONS

1. Determine how social, legal, and environmental needs screening is currently conducted in your clinical setting. How could you learn more about the "custom" screening questions that are most suitable to your clinic population? Is it possible to systematize "core" and "custom" screening items, perhaps by incorporating them into the EHR? Who would carry out these measures?
2. Collect information from cross-disciplinary providers about social, legal, and environmental community resources they use and where that information is stored. Could that information be shared across the clinical setting?
3. Discuss ways that your clinic assigns roles for social screening, referral, and follow-up. Are individual team members held accountable for their activities to screen for and address social determinants of health? If so, how? If not, why not?

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Chapter 10

Creating a Context for Effective Intervention in the Clinical Care of Vulnerable Patients

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Objectives

- Describe building a therapeutic alliance, eliciting the patient's narrative, and assessing the patient's vulnerabilities and strengths.
- Explore the four critical components of therapeutic alliance: shared values and humanity, empathy, trust, and collaboration.
- Describe the relevance of the therapeutic alliance to the effective care of vulnerable patients.
- List the benefits of eliciting the patient's narrative.
- Review common psychosocial vulnerabilities and illustrate how identifying them can help create a patient-centered clinical encounter.

INTRODUCTION

> Ms. Sviridov is a 67-year-old woman with chronic arthritis pain, hypertension, prior stroke, diastolic dysfunction, and diabetes. Despite a sizable, guideline-based medication regimen and frequent visits to both a primary care physician and a cardiologist, she has recalcitrant heart failure, requiring multiple hospital admissions. An extensive cardiac workup has been unrevealing. Ms. Sviridov is unhappy with her care and seeks out another primary care physician.

Vulnerable patients experience a triple jeopardy when it comes to health care: they are more likely to be ill; more likely to have difficulty accessing care, and when they do, the care they receive is more likely to be suboptimal. Often the suboptimal care reflects a mismatch between the psychosocial vulnerabilities that they bring to the clinical encounter and the knowledge, resources, attitudes, skills, and beliefs of the clinicians caring for them.[1]

In this chapter, we focus on the centrality of building and sustaining strong clinician–patient relationships to improve the health of our patients. Three essential strategies are recommended to promote a context for effective care for vulnerable patients: (1) building a therapeutic alliance, (2) eliciting the patient's story or "narrative," and (3) assessing for the patient's psychosocial vulnerabilities and strengths (or resilience factors). Clinicians can apply a combination of these approaches to create and sustain more productive and effective interactions and relationships with vulnerable patients (Figure 10-1).

VULNERABILITY AND THERAPEUTIC ALLIANCE

Psychosocial vulnerabilities can affect health and health care, either alone or in concert with the patient's management of the disease (see Figure 10-2). The first path is a direct one, a situation in which the vulnerability in

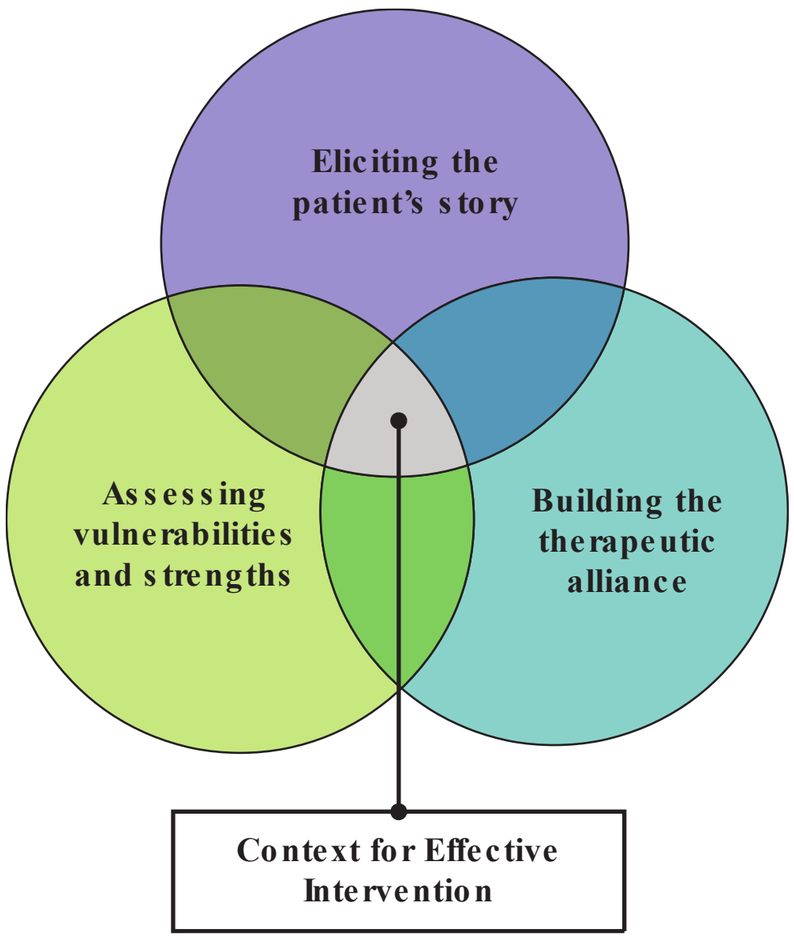


Figure 10-1. Creating a context for effective intervention in the clinical care of vulnerable patients. The care of the vulnerable patient is optimized when the clinician is able to (a) elicit the patient's story, (b) assess for vulnerabilities and strengths, and (c) build a therapeutic alliance.

and of itself leads to poor health. Concrete examples of this mechanism might be the intravenous drug abuse and skin abscesses or intimate partner violence and head trauma. A second path is an indirect one (effect modification), whereby the vulnerability attenuates or impedes the benefits of medical treatment on coexisting medical conditions, for example, the vulnerability presents a barrier to optimal acute, chronic, and/or preventive care, thereby adversely influencing the disease course. Examples of this include the negative effects of depression on adherence to medications among patients with heart disease; inability to pay for medications and poor hypertension control, or food insecurity and poor diabetes control. The third mechanism, also an indirect one, is mediated entirely through the therapeutic alliance. In this path, the vulnerability affects components of the clinician–patient relationship or the therapeutic alliance (jeopardizing open disclosure, mutual trust, caring, and engagement), thereby limiting the benefits of a collaborative relationship on care. Examples of this include a patient with an undisclosed illness that is inconsistent with a prescribed treatment plan; a clinician whose belief systems regarding addiction impedes true engagement with a patient with a substance use disorder; or a patient with depression that impedes follow-through with prescribed treatment plan, thereby leading to mutual frustration and blame.[2]

WHAT IS THE THERAPEUTIC ALLIANCE?

The term "therapeutic alliance" derives from a combination of the Greek word therapeuein (to serve) and the Latin word alligare (to bind) and was initially developed in the field of psychotherapy to describe a trusting,

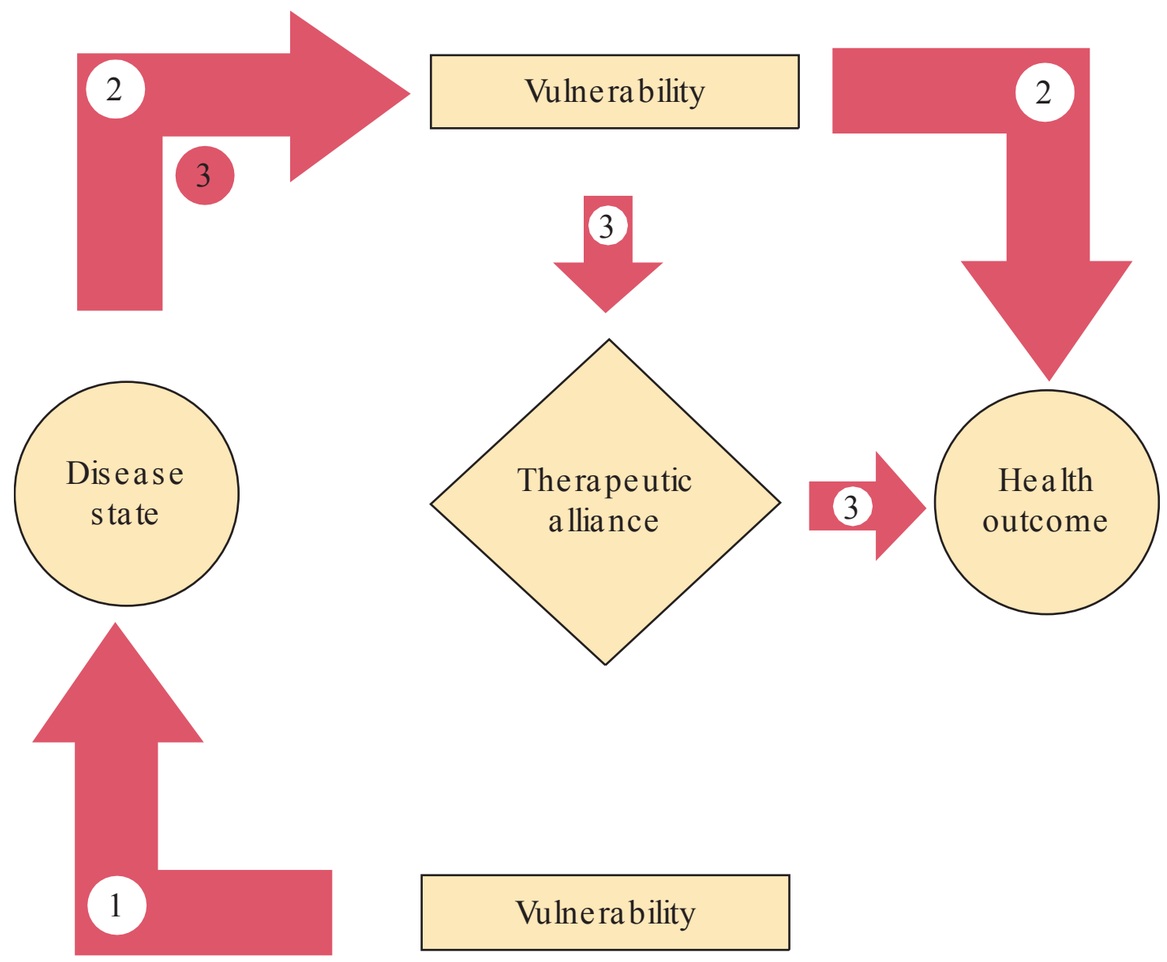


Figure 10-2. Multiple pathways by which social vulnerability affects health outcomes. In Path 1, the social vulnerability is directly linked to a disease (e.g., causal path). In Path 2, a social vulnerability impedes the patient's management of her disease, thereby leading to worse health outcomes (e.g., effect modification). In Path 3 (e.g., indirect path), a social vulnerability impairs the therapeutic alliance between a provider and patient, thereby interfering with multiple aspects of the care process necessary for the management of the disease state (diagnosis, trust, disclosure, adherence, etc.), leading to worse health outcomes.

respectful, collaborative, and caring relationship between therapist and patient. Studies demonstrated that, regardless of the theoretical model of therapy, the presence of a therapeutic alliance was associated with positive treatment outcomes.[3]

In the field of medicine, a therapeutic alliance exists when patient and clinician develop mutual trusting, caring, and respectful bonds that allow collaboration in care and treatment.[4-6] "Relationship-centered" care models build on the notion of the therapeutic alliance, and research reveals that patients reporting greater trust, increased satisfaction, shared values, and more collaborative relationships with clinicians have increased adherence to medication and treatment regimens and better health outcomes.[7-9]

Trust—Mutuality, particularly in trust, is crucial. Patients need to trust in their clinicians' integrity and competence as healers. Clinicians need to trust that patients enter the relationship trying to do their best.

Empathy—Empathy too is necessary to form a strong therapeutic alliance. Demonstrating empathy, or recognizing and understanding the beliefs and emotions of another without injecting one's own, allows the clinician to connect emotionally with the patient without pity or over identification, enriching the encounter for both. Feeling understood, particularly by your medical provider, can be profoundly comforting. Providing comfort is a reward in itself. Understanding a patient also imbues a clinician's efforts, even the mundane filling out forms, with meaning.

Respect—Expressing respect for patients and treating them with dignity are important to creating therapeutic bonds. Respect requires a willingness to take the time to understand and explain, creating a context in which communication can occur as equals.

Agreement and collaboration—Clinicians and patients both need to feel comfortable articulating and agreeing on the goals of treatment. An honest dialogue may naturally lead to disagreement about these goals or how best to achieve them. Collaboration requires a meaningful partnership in which clinician and patient perceive that they are working together toward a common goal and committed to resolving inevitable conflict. It is often helpful to explore, identify, and affirm shared values in the nonhealth domains of life so as to forge an environment of collaboration for health decisions and behaviors (i.e., values affirmation exercises).[10]

Broadening the alliance—Initially, the fields of psychotherapy and health care envisioned the therapeutic alliance as a one-to-one relationship between clinician and patient. With the influence of systems theory, this alliance has broadened to include other important people involved in the care (e.g., family, consulting clinicians).[11,12] Recent work by Wagner and others[13-15] has further highlighted the important role that health systems play in either fostering or eroding the therapeutic alliance based on the policies they promote.

THERAPEUTIC ALLIANCE AND VULNERABLE PATIENTS

A growing body of evidence suggests that it is precisely with vulnerable patients that the therapeutic alliance can be most challenging, on the one hand, yet have its most profound benefits, on the other hand. In the therapeutic alliance, clinicians offer a professional relationship aimed at helping patients feel comfortable to be as open and honest as is necessary to receive the best care. Because of their privileged position, clinicians are permitted access to the interior of patients' lives that few others are allowed. Consequently, they can build an alliance that empowers patients, reduces barriers to their care, and helps them find their inner strength.

Empowerment—Vulnerable patients often experience human relationships that are broken or disrupted (e.g., due to violence, immigration, mental illness, poverty, stigma, homelessness, illness). Through the therapeutic alliance, clinicians can offer a reliable, dependable, and continuous presence that is supportive, accepting, and nonjudgmental. They can provide safety, thus allowing patients to tell the stories of their lives and illness and disclose their vulnerabilities. By examining the patients' strengths and resources, clinicians can provide a sense of dignity and hope. Through validating patients' experiences, clinicians can help patients feel less marginalized. In supporting patients as competent and strong, clinicians can help them become actively involved in their care, increasing their agency.

Access to care and related resources—Vulnerable patients often face limited access to health care and social services. In part, they are often unaware of what is available and may not have the facility to negotiate complex, bureaucratic systems. Clinicians are in a position to remedy both of these barriers.

Through the therapeutic alliance, clinicians can help patients feel safe enough to reveal concerns or problems beyond the presenting problem, which they might not otherwise have done. For example, a patient seeking care for their diabetes may disclose that they live with an abusive partner, drink alcohol regularly, are food insecure, or are only sporadically housed. The clinician has the ability both to collaborate on treatment plans as well as facilitate entry into the various health and social systems that can address those vulnerabilities. The therapeutic alliance can help patients feel assured that clinicians will not abuse the disclosure of information (e.g., leading to rejection, stigmatization, or legal action) but will help them access resources critical for their health.

WHAT CAN HAPPEN WHEN THE THERAPEUTIC ALLIANCE IS ABSENT?

The absence of a therapeutic alliance can result in serious consequences for the health of vulnerable patients.

Mistrust—Clinicians often enter into relationships with patients assuming they share the same goals and will trust each other to do their best to attain them. However, many patients enter into the relationship with degrees of mistrust. This may result from their personal experiences with institutions in which they have felt betrayed or unwelcome, or be rooted in broader, historical experiences of their community. Clinicians should not automatically assume that they have patients' immediate, total trust; rather, they often must earn it by demonstrating trustworthiness.

Poor care—Poor and minority patients frequently receive care in teaching hospitals and community health centers where the turnover of providers can be high. Patients may question clinicians' motivation and commitment, fearing that they are educational fodder for trainees who will go on to care for the more privileged. When clinicians do not offer certain treatments, they may be suspicious about the clinicians' willingness to expend resources for them. When clinicians persuasively argue for unwanted treatments, they may fear being used as experimental "guinea pigs." Rather than raising concerns or disagreements with a clinician whose motives they question, they may choose not to follow through on recommended treatment or simply not return for care.

Disrespect—Perceived disrespect and discrimination due to race or socioeconomic status has been associated with lower satisfaction with the health-care system and worse health outcomes among patients with chronic illness.[16,17] Studies found that significant proportions of Blacks, Latinos, and Asians and those with lower educational attainment reported that they were treated with disrespect, were treated unfairly, or received worse care because of their position in society. These perceptions influenced whether patients followed recommended advice or delayed needed care for chronic illness. Communicating respect is essential to demonstrating to vulnerable patients that clinicians are willing to enter into a relationship based on equality and dignity.

Poor collaboration—In the absence of a trusting relationship, true collaboration may be difficult to achieve. Fear of being punished or treated unfairly for speaking truthfully can lead patients to withhold their beliefs and values about a suggested treatment plan, or be unwilling to follow through on a recommendation. Clinicians, in turn, can feel frustrated and mistrustful when they wonder if they are being misled or if their patients really care about their health.

Shared decision making is often promoted as a model for mutual agreement and collaboration. However, research with diverse populations suggests that clinicians and patients apparently engaging in the cardinal behaviors of shared decision making, may still not perceive that a collaborative partnership exists between them.[2] Indeed, being treated with respect and dignity may be more important than engaging in shared decision making, and lead to positive outcomes (i.e., higher satisfaction, adherence, and receipt of optimal preventive care).[18]

BUILDING A THERAPEUTIC ALLIANCE WITH VULNERABLE PATIENTS

No simple, protocol-like statements or behaviors can make another person feel cared for or respected. However, if we consciously strive to transmit a sense of trust, caring, and respect along with a desire to enter into true partnership, we increase the likelihood of forming productive relationships with patients. Some guidelines to consider in this process include the following:

DEMONSTRATE COMMITMENT TO THE RELATIONSHIP

Health-care workers need to state clearly their desire to be available to their patients within the scope of their practice (e.g., "I will be your regular doctor. Here is my telephone number with a voice mail; I check it three times a week and will get back to you as soon as possible."); define realistic expectations for what we can do between visits (e.g., "I will check into support groups and tell you at our next appointment."); and follow through on what we have promised.

ALLOW FOR THE HUMANITY OF THE PATIENT AND THE CLINICIAN TO EMERGE

The humanity of the health-care worker and the patient should be expressed and elicited. This may include the sharing of beliefs, values, and feelings as they relate to the clinical issues facing them (e.g., express concern about suffering, "I am sorry you have to deal with this pain"; self-disclosure to identify a shared history or common interests with the patient; "As a parent, I can't imagine how incredibly strong you had to be to escape with your children."). It may also include maintaining a humanistic approach in one's personal attitude and communication techniques in domains beyond health. The mnemonic "**CAPTURES**" (Box 10-1) is a very useful tool to ensure that humanism suffuses the clinical encounter and clinician–patient relationship. It has particular salience in bridging the gap for more "difficult patients."[19]

ELICIT PATIENTS' STORIES OR HEALTH "NARRATIVES"

This interviewing approach provides critical insights into a patient's illness model, allows for expression of the

BOX 10-1. Personal Attitudes and Techniques to Enhance a Sincere Humanistic Component in the Encounter (mnemonic: "CAPTURES*")

C = Curiosity/Interest
Adopt a warm, sincere, friendly **Curiosity** or interest about your patient's personal aspects

A = Appreciate/Admire
Find something to warmly **Appreciate** or **Admire** in your patient

P = Point of View
Always try to see things from the **Patient's Perspective/Point of View**

TU = Touch and Use
Touch the patient and **Use** other body language (proximity, attention, smile) to show caring

RE = React
React to what the patient says or does and how. Take notice!

S = Support and Stress
Support the patient by **Stressing** any positive aspects, providing reassurance and hope as much as possible

***= Continue**
Continue this approach in future encounters: When there is more to be accomplished than time allows, postponement and organizing a future appointment facilitates the relationship.

From Schattner A. The silent dimension: Expressing humanism in each medical encounter. Arch Intern Med 2009;169:1095-1099. doi:10.1001/archinternmed.2009.103.

patient's humanity, and uncovers important psychosocial vulnerabilities (see later). The widespread growth of computers to access the patient's electronic health record (EHR) may be an impediment to the clinician–patient relationship, especially listening to the patient tell the "story" of her disease—a skill long considered essential to the art of medicine.[20,21] Clinicians should employ periods of noncomputer use to ensure direct eye contact with the patient so as to demonstrate active listening and promote mutual understanding. Designing the physical layout of the exam room to ensure that the clinicians do not have their back to the patient and/or the family members while on the computer is an important step. Completely walking away from the computer to answer questions is an effective maneuver. Using the EHR to show the problem list, the medication list, the patient's test results, and flow charts of important information can help the patient appreciate the value of the EHR in their care.

SEARCH ACTIVELY FOR PATIENTS' STRENGTHS AND RESOURCES

We commonly focus on what is wrong or dysfunctional in the patient's life. An added search, and one just as vigorous as the search for deficits, is to identify and validate the strengths and resilience each patient has (e.g., "You have been through a lot of suffering in your life, how have you been able to survive?" "Who gives you the strength to deal with difficult things?"). Reflecting on how the patient has used these resources in previously difficult times can provide a positive starting point for healing (e.g., "You have talked about turning to God when dealing with other major crises in your life; have you thought of doing that now?"). The power for healing does not rest solely with the clinician, but must involve an empowered patient, their family (e.g., "Your sister gave you strength to leave an abusive relationship; can she help now in dealing with your diabetes?"), and their communities (e.g., "Your mother really enjoyed the Samoan center day program before she died; has your father considered going?"

EXPRESS CARING OVERTLY

We need to clearly state that we care about our patients as people, and not assume they know. When hearing patients' describe difficult or painful experiences, we can acknowledge our patients' perspective (e.g., "I can't imagine how difficult your life has been"; "What you have lived through sounds so frightening" ; "I know you're afraid going through these tests and treatments; what can I do to make it less scary?").

A number of nonverbal behaviors and verbal statements can also overtly express that we care: (a) body language (e.g., sitting in proximity; a focused, unhurried posture); (b) active listening and re-framing (e.g., "You felt betrayed by the people you trusted most; is that right?"); (c) support (e.g., "I know you are trying very hard to live on your own for the first time; I think you are doing great, and I want to do whatever I can to support you."); and (d) validation (e.g., "You deserve to feel safe in your home.").

Caring can also be communicated in a number of indirect ways, such as making an unexpected phone call to follow up with a patient in crisis (e.g., "I wanted to see how you are doing after your colonoscopy yesterday"). Not all patients (nor clinicians) are comfortable with touch. However, some patients believe clinicians are afraid to touch them. Maintaining physical contact during painful or uplifting moments can activate a mutual human connection.

CREATE A CONTEXT FOR CONFLICT TO EMERGE AND GET ADDRESSED

Patients need to hear that we are open to discussing how their beliefs or feelings differ with ours. We must allay their fears that voicing disagreement will incur displeasure or even punishment from clinicians. Similarly, patients need to know that they can change their

minds about treatment plans and decisions at any time. Patients need repeated reassurance and reminders that disagreement will not cost them the clinician's regard and care (e.g., "I appreciate hearing my patients' concerns or doubts about a plan. I will not be angry or upset because together we can figure out the best thing to do"). Building a therapeutic alliance does not require us to deny our informed viewpoint, but rather to adopt nonthreatening ways of communicating differences with our patients. Creating this space can improve efficiency in the long term by allowing clinicians to hear and address concerns earlier in a treatment plan.

CLARIFY BOUNDARIES

Vulnerable patients may often experience considerable intrusion into their personal lives by government institutions or social service agencies. They may be required to disclose more information than others and find it shared across agencies without their knowledge or permission. We should clarify why we are inquiring about certain information (e.g., "I want to ask more specifically about your family because they seem important in your care, and I want to understand how they help you.") and what is confidential or required to be shared (e.g., "I will keep whatever you tell me confidential unless I think you may harm yourself or someone else; then I must tell others to protect you from any harm."). Clinicians should also clarify their own boundaries to reduce the risk that such relationships will generate unhealthy dependence or unrealistic expectations.

ADDRESS THE THERAPEUTIC ALLIANCE DIRECTLY

When caring for a patient who is doing poorly clinically but receiving optimal "medical" management, we should consider if the therapeutic alliance needs attention. We can directly state our desire to have a strong relationship and a real sense of partnership. We can ask if the patient would want any changes in our relationship, reassuring her that speaking honestly is not only acceptable but essential to working together.

ELICITING THE PATIENT'S STORY, OR "NARRATIVE"

> Ms. Sviridov's new primary care physician, deciding to focus on the therapeutic alliance, invests the time in the visit agenda to ask about her life. She describes an active singing career, a rich family life, and the importance of her church. She acknowledges that profound depression and concern over the welfare of her drug-abusing son interfere with her caring for herself.

WHAT IS THE PATIENT'S PERSPECTIVE?

Many factors (individual, familial, societal, spiritual, and cultural) shape a person's concept and experience of health and illness. These inform an individual's sense of responsibility as a patient; expectations of health-care providers and family members; and the meaning of healing and recovery. Personal concepts of health determine what preventive and self-care behaviors are considered appropriate, which symptoms seem worrisome, and when to seek help from health-care professionals. These explanatory models encompass the meaning of the illness, the presumed cause, its proposed trajectory, the degree of hope of cure, and how treatment should be conducted.[22]

The same factors that influence how a person thinks about health and illness obviously affect other aspects of his life, and eliciting information about these influences can unveil perspectives important to health care. For example, how an individual makes decisions about health care may resemble how he makes decisions about parenting or work; the process for how a family decided to immigrate to the United States may be very similar to how they will approach a difficult treatment decision; one's explanation of life difficulties and the narrative of how one has prevailed over them may illustrate how one will face challenging health problems as well. For example, illness may be framed hopefully or pessimistically; patients identify themselves as successful or as victims, or as independent, isolated, or strengthened by support from others.

IMPORTANCE OF ELICITING THE PATIENT'S PERSPECTIVE

A patient's perspective, a complex mixture of very personal beliefs, values, and assumptions reflecting multiple influences, can determine how a patient develops a relationship with her clinician, and whether she feels understood and respected or misunderstood and discounted. Clinicians, in turn, have their own individual perspectives on health and illness, and ascribe specific meaning to their role as healers. Assuming a shared understanding and not exploring these differences may in fact lead to greater distance and misunderstanding. Eliciting patients' perspectives allows for accurate empathy and can uncover interests or experiences common to both patient and clinician, thereby reducing the social distance that often impedes the development of a therapeutic alliance.

Eliciting of the patient's story can improve patient trust, satisfaction, and adherence. In a meta-analysis of the effect of physician communication on health, Stewart et al[9] found that effective communication within the history-taking section of the visit consistently correlated with improved health outcomes, including emotional health, symptom resolution, function, physiologic measures (e.g., blood pressure and blood glucose), and pain

control. In their study of patient trust, Thom et al[23] found that physician's receptive communication behaviors such as "letting the whole story be told" was associated with patient trust, satisfaction, and adherence. Clinicians also benefit from understanding their patient's stories. This enriches and brings meaning to interactions and allows clinicians to be both more effective and engaged.

Furthermore, sometimes the way people frame their illnesses can amplify or cause suffering. Within the context of a strong therapeutic alliance, it is even possible to recast some narratives as part of the healing process. A patient who feels incompetent, for example, might grow, through learning to control their illness, to feel capable and empowered in realms beyond the medical.

ASSESSING AND ACKNOWLEDGING PSYCHOSOCIAL VULNERABILITIES

> Ms. Sviridov's physician suggests he make a home visit. Exploring her initial refusal, he learns that her son deals drugs from her apartment. His home visit reveals a chaotic environment and discovers that her son often steals her medications in the hope of finding opiates. Eventually, with the assistance of her physician and adult protective services, she is able to demand that her son leave. She receives support and assistance from home-health services and her church group. Her conditions stabilize and she is no longer re-hospitalized for heart failure.

Much of clinical training and guideline development focuses on pathophysiology, disease, diagnosis, and treatment. Seasoned clinicians, however, are acutely aware of the gap between the outcomes that are expected (e.g., from reading textbooks or following guidelines) and the outcomes that are actually achieved in practice. While there are many reasons for the observed variation in quality and health outcomes, one of the most important and frequently least appreciated factors is the patient's social context. A wide range of psychosocial vulnerabilities can impinge on a patient's ability to carry out the treatment plan and interfere with the therapeutic alliance (see Box 10-2).

When faced with a patient who is doing poorly from a clinical standpoint, many clinicians may not reflect on the psychosocial factors that may be influencing the patient's course. Some clinicians simply throw up their arms and attribute a patient's clinical decline to his/her social milieu in a global or at times derogatory fashion, referring to such a patient as "nonadherent," a "difficult patient," a "train wreck," or a "social nightmare," without digging deeper. Some clinicians often believe that addressing psychosocial problems is "not my job," stating, "I can't fix his social problems." Still others may not have the communication skills to uncover underlying psychosocial problems, or to address them and integrate this knowledge into treatment plans, thereby forging a more genuine, engaged therapeutic alliance. Finally, clinicians may feel powerless and overwhelmed by their patients' situations, with their empathic compassion causing a kind of secondary trauma.

BOX 10-2. Generating a Differential Diagnosis of Psychosocial Vulnerabilities

Violence and trauma
Uninsured
Literacy and language
Neglect and abuse
Economic and food insecurity
Race/Ethnic discordance, discrimination
Addiction
Brain disorders, e.g., depression, dementia, personality disorders
Immigrant status
Legal status (parole, probation, undocumented)
Isolation/Informal caregiving burden
Transportation problems
Illness model
Eyes and ears
Shelter (housing instability or homelessness)

Screening for psychosocial vulnerabilities is central to caring for patients in any setting and at multiple points during the process of care, particularly when treatments appear to be failing. Some vulnerabilities will be apparent from the first encounter, while others may be hidden. For some patients and problems, it is not until a collaborative relationship has been established that a patient feels comfortable enough to disclose sensitive information. Similarly, patients may perceive a problem to be irrelevant to their health and neglect to discuss it.

When assessing for areas of vulnerability, the clinician should be nonjudgmental, allowing the patient to respond at his/her own pace. Using open-ended questions and responding to patient cues may enable a patient to reveal the important nonclinical factors that may be impeding their progress.

Brief screening instruments, many of which have been validated cross culturally and in non-English languages, can also be useful. They exist for many problems and are discussed extensively in other chapters. (See, e.g., Chapter 35, Intimate Partner Violence, and Chapter 39, Principles of Caring for People Who Use Alcohol and Other Drugs.)

It is important to raise four important caveats about assessing for psychosocial vulnerability (Box 10-3). The first is that in the pursuit of identifying vulnerability, the clinician should be reminded of the importance of

Box 10-3. Common Pitfalls in Assessing for Vulnerability

- Not recognizing the contribution of psychosocial vulnerabilities to the patient's illness
- Not acknowledging vulnerability nor exploring how the vulnerability may be affecting care.
- Not addressing the vulnerability
- Not integrating knowledge of the vulnerability into treatment plans.
- Not recognizing the shame and stigma associated with vulnerabilities
- Neglecting to identify and acknowledge strengths, resilience, and a range of resources

simultaneously identifying and acknowledging an individual's strength, resilience, and range of resources, such as one's belief in a higher power or support from a religious community, or the love and support provided by a spouse, friend, or pet. Reflecting back to patients' examples of how they have overcome difficulty in the past and identifying patterns of success is critical to building self-efficacy and developing a therapeutic alliance in the face of vulnerability.

Second, vulnerability is context dependent. For example, in countries with universal health-care coverage, lack of insurance is simply not a vulnerability. Conversely, absence of interpretation services may exacerbate the effects of limited English proficiency when compared to settings with interpretation; presence of a methadone treatment program or a mobile treatment van in one's clinic may mitigate the untoward health effects of heroin addiction and housing instability, respectively. As such, altering the context in which care giving takes place, which most frequently means adapting the clinical encounter, can influence the effects of vulnerability on health care. This suggests that when caring for vulnerable populations, clinicians and systems should also perform self-assessments, and carefully explore the ways in which the care-giving context can be adapted to best attenuate (or even eliminate) the health effects of vulnerability.

Third, in the process of assessment, the clinician should be sensitive to the concerns of patients with respect to shame and stigma.[24] A number of factors listed in Box 10-2 may elicit feelings of shame, such as having limited literacy, being marginally housed, having mental illness, or being addicted.

Fourth, after identifying a vulnerability, exploring with the patient, in a supportive and nonjudgmental manner, how the vulnerability may be affecting both health and care and how to mitigate these effects is an important next step. Only by doing so can the clinician develop a more effective treatment plan while simultaneously enhancing the therapeutic alliance.

SUSTAINABILITY IN BUILDING THE THERAPEUTIC ALLIANCE WITH VULNERABLE PATIENTS

A number of additional strategies may be especially useful for developing and sustaining a therapeutic alliance with socially vulnerable patients. These include showing patients in concrete ways that you care (i.e., "going the extra mile"); advocating for patients with the myriad bureaucracies that they struggle with; connecting them to appropriate community resources (e.g., immigration lawyer, domestic violence counselor, exercise groups); networking with others, including family, friends, public health, and community resources, so as to encourage them to support the patient's efforts to achieve health; engaging in self-disclosure to narrow down social distance; and encourage the sharing of personal stories.

Building a therapeutic alliance with vulnerable patients comes with both special rewards and challenges. Working with the underserved allows a clinician to apply his or her skills to assist those who are most in need, fulfilling one of the basic humanitarian ideals in medicine. Developing a therapeutic bond with patients that do not represent the "typical patient," or that many consider too difficult to manage, can be rewarding in and of itself, often involving a process of shared discovery and reflection.

It is not uncommon, however, for even seasoned clinicians to become overwhelmed by the many challenges inherent to caring for vulnerable patients. Developing patterns of codependency, such as repeatedly "rescuing" patients from the decisions that are in their control, may be a prelude to clinician "burnout." In addition, the work environment plays an important role. Although clinicians in underserved clinical settings report serving higher proportions of medically and psychosocially complex patients, they are more likely to report a chaotic work environment and less likely to feel in control.[1,25] In these contexts, clinicians who perceive high proportions of challenging patient encounter have higher odds of burnout and reduced job satisfaction.[1]

Recognizing the signs of "burnout" in themselves and their colleagues, such as exhibiting anger and frustration at patients or staff or developing an overly passive style of patient engagement, is important for all clinicians. The topic of preventing clinician burnout and finding ways to thrive when caring for vulnerable patients is covered in detail in Chapter 45. Briefly, to minimize burnout and maximize sustainability, clinicians caring for vulnerable populations may draw on personal, interpersonal, and environmental supports. In a qualitative study exploring why clinicians work in underserved clinics, clinicians cited the importance of personal motivators (such as opportunity for personal growth and concordance of service with self-identity and mission-based values)[26]; career motivators (such as work–life balance and loan repayment

assistance); and environmental factors, primarily supportive interprofessional colleagues and teams.[26] Sustaining these motivators requires mindful practice, "purposeful and nonjudgmental attentiveness to one's own experience, thoughts, and feelings."[27] In turn, more mindful clinicians can engage in more patient-centered communication and build more successful relationships.[28]

Clinicians who have been able to sustain therapeutic relationships with vulnerable patients and maintain fulfilling careers in the care of vulnerable populations tend to (a) elicit patients' agendas so as to establish an understanding of patient expectations; (b) set realistic goals for what they can accomplish and share these goals with their patients; (c) limit what they aim to accomplish in any given encounter and see their work with patients as evolving over a long period of time (a therapeutic arc); (d) continually clarify boundaries; (e) maintain a sense of curiosity and discovery about the patients' clinical and personal profile; (f) acknowledge that many of the problems experienced by vulnerable patients are structural/societal in nature, and not always a result of patient choice; (g) engage in public health-related or social advocacy efforts to affect structural determinants of health; (h) seek the advice and support of colleagues who share common ideals and practices; (i) and engage with interprofessional colleagues to draw on their expertise as part of an integrated team. Health-care systems wishing to recruit and retain clinicians caring for vulnerable populations need to provide opportunities for clinicians to develop these intra- and interpersonal skills and enhance the clinical resources that allow clinicians to feel successful in their work.

CONCLUSION

Depending on the skills, attitudes, and orientation of clinicians and the systems in which they work, the clinical encounter can increase social distance and exacerbate the effects of vulnerability on health, or can promote productive engagement with patients to mitigate or even eliminate the effects of vulnerability on health. A strong therapeutic alliance creates a trusting context for patient care. Building a therapeutic alliance, eliciting the patient's narrative, and assessing for vulnerabilities and strengths are critical to creating this context. Fostering the therapeutic alliance with vulnerable patients involves identifying our shared humanity, developing trust, conveying empathy, and collaborating around treatment goals. To maximize sustainability, clinicians caring for vulnerable populations should draw on personal, interpersonal, and environmental supports. Working with vulnerable populations, while challenging, allows a clinician to fulfill one of the central humanitarian ideals of the healing professions.

- Vulnerable patients often experience fragmentation and disconnection in their lives and in their health care.
- The therapeutic alliance is an important means to reduce the effects of vulnerability on health outcomes
- Eliciting the patient's story or perspective is an effective means to uncover health beliefs, develop shared meaning, enable empathy, foster the therapeutic alliance, uncover patient vulnerabilities, and reveal their resilience.
- Identifying vulnerabilities and acknowledging to the patient and to other clinicians involved in the patient's care how such factors might influence the effectiveness of treatment, clinicians will be better equipped to develop successful treatment plans.
- Eliciting a patient's story and forming a strong therapeutic alliance strengthen a clinician's satisfaction with caring for patients.

Eliciting the Patient's Perspective

- Let patients know that hearing their perspective is important to you.
- Explain why you think discussing family, coping styles and the like, is important to their health.
- Take the time necessary, and use the time well
  - Set a climate of interest, concern, and calm.
- Use an inquiry style that fosters more, not less, information.
  - Maintain a high degree of curiosity, be aware of patient's verbal or emotional cues
  - Follow-up on cues—such as "it seemed that talking about that brought up some feelings for you. Why is that?"
- Use open-ended questions and reflective statements.
- Discover the patient's explanatory model.
  - Ask the Kleinman questions:
    What do you call the problem? What do you think has caused the problem? Why do you think it started when it did? What do you think the sickness does? How does it work? How severe is the sickness? Will it have a short or long course? What kind of treatment do you think you should receive? What are the most important results you hope to receive from this treatment? What are the chief problems the sickness has caused you? What do you fear most about the sickness?[22]
- Consider the interpersonal context of patients' general health-care framework (see Chapter 22, The Family as the Context for Care).
- Focus on the meaning of what patients are saying.
- Avoid using technical, medical jargon.
- Do not try to gather the entire perspective in one appointment, but try to gain some insight every time.

DISCUSSION QUESTIONS

1. Discuss clinical experiences you have had with vulnerable patients in which the presence or absence of strategies such as building a therapeutic alliance, eliciting patients' narratives, and assessing for vulnerabilities and/or strengths influenced the process and perhaps the outcome of their care.
2. Consider what structural and health policy changes would need to be made to better incorporate the strategies of building a therapeutic alliance, eliciting patients' narratives, and assessing for vulnerabilities and strengths into the day-to-day clinical care of vulnerable patients.
3. What are some of the most surprising or fascinating nonmedical pieces of information you learned about the last patient you cared for, and how did it influence either the treatment plan or your relationship with the patient and his/her family?
4. Discuss how our personal beliefs, values, and assumptions about vulnerable patients affect your ability to create a context for effective care using strategies such as building a therapeutic alliance, eliciting patients' narratives, and assessing for vulnerabilities and strengths.

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Chapter 11

Creating the Medical Home for Underserved Patients

Reena Gupta, MD and Thomas Bodenheimer, MD

Objectives

- Define the patient-centered medical home.
- Review the rationale for the medical home model and a high-performing primary care delivery system.
- Describe the 10 building blocks of high-performing primary care.
- Discuss the challenges and opportunities of creating medical homes in safety-net settings.

Mrs. C is a 58-year-old Spanish-speaking woman with poorly controlled diabetes, hypertension, and obesity. She works as a housekeeper and frequently has to miss visits with her primary care provider (PCP) because of work. Mrs. C's PCP has a panel of 2000 patients, sees 30 patients per day, and does not speak Spanish. During her routine 15-minute visits, her PCP explores Mrs. C's symptoms of back pain and depression using her daughter as an ad hoc interpreter, reviews her HbA_{1c} of 9.5 and blood pressure of 160/100, and recommends dose adjustments to her medications. The PCP feels that there is not enough time to explain illnesses and treatments to Mrs. C. and worries that they do not get to preventive care. At the end of a visit, both Mrs. C and the PCP are often dissatisfied with the encounter. Despite the PCP's best intentions and hard work, Mrs. C's chronic conditions do not improve.

INTRODUCTION

Primary care in the United States is at a crossroads. With skyrocketing costs, fragmented care, limited access, and the primary care physician shortage, primary care needs to undergo substantial transformation. The patient-centered medical home (PCMH) is widely advocated as a model to address the challenges of primary care and achieve what the Institute for Healthcare Improvement calls the "triple aim"—better population health, improved patient experience, and reduced per capita costs.[1]

The PCMH model aims for "comprehensive, continuous, patient-centered, team-based, and accessible primary care delivered in the context of a patient's family and community."[2] The model first originated from the American Academy of Pediatrics in 1967 and was endorsed by the four main primary care professional societies in the 2007 "Joint Principles of the Patient-Centered Medical Home."[3-4] The Affordable Care Act (ACA) calls for implementation of the medical home, and multiple public and private groups have supported widespread medical home demonstration projects.[5-7] With these efforts, the number of practices undergoing medical home transformation nationwide has grown rapidly.

The medical home model is especially important in safety-net settings that provide primary care to underserved communities. Vulnerable populations face substantial barriers to care including limited access, low English proficiency, low health literacy, psychosocial complexity, and multiple medical comorbidities. Given its emphasis on access, whole-person orientation, team-based care,

and care coordination, the PCMH model has the potential to address the many concerns of vulnerable populations.[8]

Providing patients with insurance coverage and a medical home has been found to reduce racial and ethnic disparities in access and quality of preventive and chronic care and to improve outcomes for vulnerable patient populations.[9] Safety-net clinics, however, face additional challenges to the transformation required to adopt the PCMH model. They frequently have unstable sources of funding, limited resources, high staff turnover, and heavy patient demand.[10-11] Policies and payment reform that promote medical home transformation in safety-net settings could help reduce disparities among underserved communities.

This chapter discusses the background of the medical home and presents a framework for creating the medical home—the 10 building blocks of high-performing primary care.[12] We will highlight the salient aspects of medical home implementation in safety-net settings serving vulnerable populations.

WHAT IS PRIMARY CARE?

Primary care is "the provision of integrated, accessible health-care services by clinicians who are accountable for addressing a large majority of personal health-care needs, developing a sustained partnership with patients, and practicing in the context of family and community.[13] Barbara Starfield, a foremost authority on primary care, describes four pillars of primary care practice: first-contact care, continuity over time, comprehensiveness, and coordination with other parts of the health system (Box 11-1).[14]

THE VALUE OF PRIMARY CARE

A health system based on the principles of primary care is likely to have better quality, improved patient experience, and reduced costs—the triple aim.[15] Primary care is more likely to provide recommended preventive services[16] and patients are more likely to be satisfied with their care.[17] Nations with a larger ratio of primary care physicians to specialists tend to have lower per capita health expenditures.[18] Similarly, a study from 2004 showed that states in the United States with more generalists have higher quality of care and lower per capita Medicare expenditures, while states with more specialists per capita have the reverse.[19]

Box 11-1. Four Pillars of Primary Care Practice

Pillars	Characteristics
First-contact care	Single door through which patients can enter the health-care system
Continuity over time	Patients and families have a regular source of care over a significant period
Comprehensiveness	Whole-person orientation, addresses primary care's responsibility to deliver all types of health services—preventive, acute, chronic, palliative, supportive
Coordination	Refers to the integration of a patient's care no matter where or by whom the care is obtained

CHALLENGES IN PRIMARY CARE

While primary care is essential as the foundation of any health-care system, primary care in the United States has serious shortcomings. While half of physicians in most nations practice primary care, only one-third of US physicians practice primary care, creating a chronic primary care shortage. Primary care is unevenly distributed across the United States. The ratio of primary care physicians to population is half in rural areas compared with urban areas; similar disparities exist for economically disadvantaged urban areas. A total of 65 million people in the United States (about 20%) live in areas designated as primary care health professional shortage areas. These communities have high proportions of uninsured, poor, and minority populations with higher death and disease rates than in communities with better access to primary care. From 1998 to 2006, the number of counties with medically disenfranchised populations increased by 52%.[20]

In 2013, 52% of Americans reported being unable to get a same-day or next-day appointment when they were sick; 26% waited 6 days or more for an appointment. Only 35% of primary care practices offer after-hours care. Forty-eight percent of Americans used an emergency department in the past 2 years, often because they were unable to gain access to primary care.[21] Access to care is particularly difficult for patients who are uninsured or insured through Medicaid. In 2011, 31% of physicians would not accept any new Medicaid patients. Thus, uninsured patients are left to seek care in stressed county-run health systems or community clinics that often lack the capacity to care for all the patients needing assistance.[22]

Even when patients can access primary care, their visits are often rushed and their problems are not addressed. Fifty percent of patients leaving a physician visit report that they do not understand what the physician said.[23] In an audiotaped study, patients making an initial statement of their problem were interrupted after an average of 23 seconds.[24]

Primary care practices are often hectic, concentrating much of the work in the hands of overly busy and often burned-out physicians. Nonphysician staff are not usually trained or empowered to contribute to the care of patients. Continuity of care can be poor, and the practice may not address the needs of the entire practice population. Care

is often driven by urgent patient concerns, and chronic disease care may be neglected. In the words of the nation's leading health-care champion Donald Berwick, "We are carrying the 19th-century clinical office into the 21st-century world. It's time to retire it."[25]

THE CAMPAIGN TO IMPROVE PRIMARY CARE

In 2007, the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association united around a vision for primary care—the joint principles of the PCMH, an elaboration of the four pillars of primary care articulated by Barbara Starfield in 1998.[4,14] Propelling this effort was the willingness of some payers, including government, to consider enhanced payments to practices meeting certain qualifications.

In 2008 (modified in 2011 and 2014), the National Committee for Quality Assurance (NCQA) unveiled a PCMH recognition process with specific requirements.[26] Other US organizations have developed their own recognition programs. Primary care practices find PCMH standards useful for targeting their improvement efforts; however, the PCMH recognition process has come under criticism. Practices may receive recognition without transforming themselves in a fundamental way. Some feel the NCQA requirements overemphasize technology and that the checklist does not accurately capture needs of patients and practices.[2] A study of 30 Los Angeles community health centers found no association between NCQA medical home scores and the quality of diabetes care.[27] Recognition standards function more as an assessment tool to guide transformation rather than a representation that successful practice transformation has been achieved.

In 2012, the University of California San Francisco (UCSF) Center for Excellence in Primary Care developed a conceptual model for fundamental primary care transformation, the 10 building blocks of high-performing primary care (Figure 11-1).[12] The remainder of this chapter describes the building blocks, emphasizing their relevance to vulnerable populations.

> Mrs. C switched to a community health center offering a PCMH model of care, and she was connected to a new PCP and care team. She was linked to a trained Latina medical assistant who provided health coaching and a nurse who saw her for planned chronic disease group visits, giving her the knowledge, skills, and confidence to better self-manage her diabetes, blood pressure, and back pain. An onsite behaviorist on her care team engaged Mrs. C for her depression. Mrs. C agreed to make concrete lifestyle changes and learned the proper instructions for taking her medications. Within 6 months, her HbA_{1c} dropped to 7.2%, her blood pressure to 135/85, and her mood had improved.

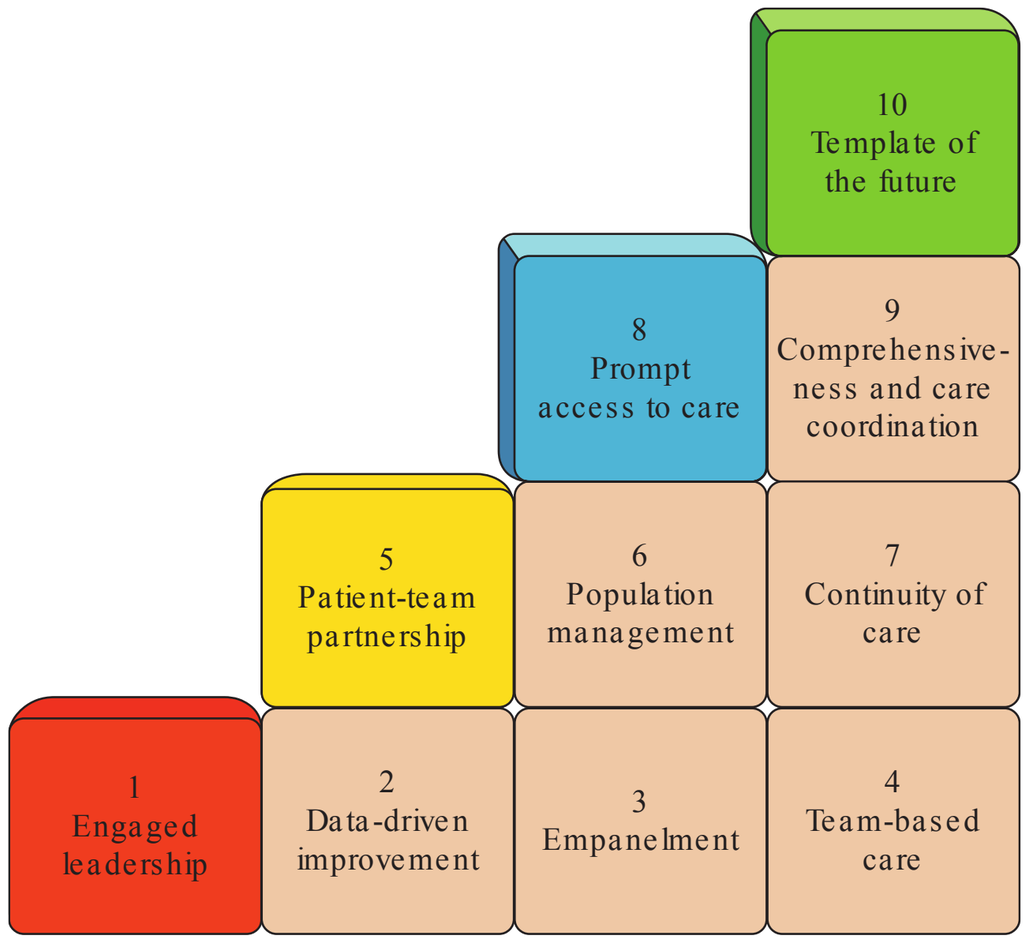


Figure 11-1. Building blocks of high-performing primary care. (Bodenheimer T, Ghorob A, Willard-Grace R, Grumbach K. The 10 building blocks of high-performing primary care. Ann Fam Med. 2014;12:166–171.)

THE 10 BUILDING BLOCKS

The building blocks were developed from observations of 23 high-performing primary care practices in the United States. While practice settings varied widely (small private offices, community health centers, and hospital-based or in large delivery systems), internally they looked surprisingly similar in their consistent implementation of 10 elements of primary care transformation (Figure 11-1).

BLOCK 1: ENGAGED LEADERSHIP

Engaged leadership, including physicians, staff, and patients, create a practice-wide vision with concrete goals and objectives. High-performing practices have leaders who are fully engaged in the process of improvement and who learn how to facilitate organizational transformation. High-performing practices have leadership at each level of the organization. Medical assistants, receptionists, clinicians, and other staff are involved in leading efforts to improve workflows.

Many community clinics actively engage patients in the transformation process, as the majority of their boards are composed of consumers.[28] Patients act as experts in the health-care experience to identify priorities for improvement. In clinics with high proportions of vulnerable populations, leaders need to prioritize services specific to vulnerable populations such as language-concordant staff, health coaching, on-site behavioral health staff, or low literacy education materials. Leaders create concrete, measurable goals and objectives, such as the percent of

our patients with diabetes who have a HbA_{1c} greater than 9 will drop from 20% to 10% by June 30, 2016.

BLOCK 2: DATA-DRIVEN IMPROVEMENT USING COMPUTER-BASED TECHNOLOGY

Monitoring progress toward objectives requires the second building block: data systems that track metrics across the triple aim—clinical (e.g., cancer screening and diabetes management), operational (continuity of care and access), and patient experience and staff satisfaction metrics. In addition to traditional metrics, high-performing safety-net practices also measure data to identify disparities in care, and target improvement efforts to reduce these disparities. Performance measures are often communicated to each clinician and care team and regularly shared with the entire staff to stimulate and evaluate improvement. Data dashboards may be displayed in prominent locations within the practice and performance data are discussed in team meetings. For many safety-net systems, data-driven improvement will require replacing outdated technology with robust health information technology (HIT) systems with patient registry functions to measure and track outcomes.

BLOCK 3: EMPANELMENT

Empanelment means linking each patient to a care team and a personal primary care clinician. Empanelment is the basis for the therapeutic relationship that is essential for good primary care.[29] Empanelment enables the practice to calculate adjusted panel size, by which complex patients are given additional weight in order to adjust panel targets for patient complexity. The goal of adjusted panel size targets is to estimate whether each clinician and team can reasonably provide care that meets the patients' needs. Patient demand exceeding capacity can impede prompt access to care. Empanelment allows practices to distribute the workload evenly among clinicians and teams.

Defined panels provide a denominator for performance measures. How does a clinician know the percent of his/her diabetes patients with HbA_{1c} levels above 9? The clinician needs to know the denominator—how many patients with diabetes are in her panel. Empanelment is also essential for identifying the patient population and stratifying by need for population management.

Unfortunately, in many safety-net clinics, patients are not empaneled to a specific primary care provider. In a survey of 554 safety-net health centers, 48% reported lacking a process for scheduling patients with a personal primary care provider.[30] In addition, patients may have financial stressors such as changes in insurance status, changes of address or phone numbers, or competing priorities for securing housing and food that interfere with connecting to a usual source of care.[31] In order to achieve empanelment, safety-net practices may need to limit the number of patients they accept in order to right-size panels and provide optimal care for their established patients.

BLOCK 4: TEAM-BASED CARE

High-performing practices view teams as necessary for the practice of adult primary care. It is estimated that a primary care provider with an average panel of 2000 patients would spend 17.4 hours per day providing recommended acute, chronic, and preventive care without the support of a care team.[32] Many exemplar practices have created teams with well-trained clinical assistants who add primary care capacity and "share the care."[33]

One problem with large teams is that a patient might not be able to identify one or two team members who know her well. To address this issue, high-performing practices generally organize their teams around "teamlets"—a stable pairing of a clinician and clinical assistant who work together every day and share responsibility for the health of their panel.[34] Some practices have increased productivity or panel size by having two to three clinical assistants for each clinician. Often a larger team—perhaps a registered nurse (RN), social worker, pharmacist, and behaviorist—supports several "teamlets."

Some high-performing practices introduce side-by-side colocation of clinicians and nonclinician staff in common work areas (sometimes called pods), agree on ground rules that establish a respectful and mutually appreciative culture, perform daily huddles to discuss anticipated patient needs, and write standing orders empowering nonclinician staff to share the care. Practices may increase the size of their panels by assigning a subpanel of patients with uncomplicated chronic conditions to RNs or pharmacists, who help manage a chronic condition using standing orders and algorithms. High-performing teams have clearly defined roles for each team member, and dedicate resources for training and skills checks to reinforce these roles.

High-functioning teams are the cornerstone of the medical home, and one of the most powerful practice-level interventions for improving care of vulnerable populations. In the Safety Net Medical Home Initiative survey, more than half of the 554 safety-net health centers surveyed reported that nonphysician staff members did not share responsibility for managing patient care prior to the medical home intervention.[30] Research has shown that team-based care can improve health-care quality and reduce disparities among underserved patients with chronic disease.[35,36] Overburdened practices caring for disadvantaged populations can benefit from teams which allow physicians to focus on complex clinical care and empower team members to work at the highest level of their licensure to support vulnerable patients through proactive visit planning, care navigation, and self-management support.

BLOCK 5: THE PATIENT–TEAM PARTNERSHIP

An effective partnership recognizes the expertise that patients bring to the medical encounter as well as the evidence base and medical judgment of the clinician and team. Patients are not simply told what to do but are engaged in shared decision making that respects their personal goals. For patients with chronic conditions, health coaching provides a framework for self-management support.[37]

Patient-centered communication strategies are especially critical when caring for vulnerable populations with low English proficiency (see Chapter 31) or limited health literacy (see Chapter 15). Patient-centered interactions (such as asking patients about their beliefs, using shared decision making, teach back, motivational interviewing, and low literacy education materials) lead to enhanced patient decision making, health behavior change, and disease self-management. A patient–team partnership relies on communication in the patient's preferred language with the use of bilingual clinicians or trained interpreters, which have been shown to increase patient centeredness of encounters, reduce disparities in the use of preventive services, increase care quality, and improve satisfaction.[38,39] Self-management support programs result in improved health outcomes among diverse populations with low health literacy in safety-net settings.[40,41]

When asked about their priorities for primary care, patients often recognize the importance of having a strong partnership with their primary care provider and care team. In a study of patient perspectives on the PCMH model, some of the priorities identified by disadvantaged, chronically ill safety-net patients were as follows: (1) strong communication and partnership with their physician, (2) personal responsibility and proactive participation in their care, and (3) education and support resources to help them better manage their care.[42]

BLOCK 6: POPULATION MANAGEMENT

High-performing practices stratify the needs of their patient panels and design team roles to match those needs. Three population-based functions provide major opportunities for sharing the care: panel management, health coaching, and complex care management.

Panel Management

Panel management involves the active management of panels of patients to identify and close chronic and preventive care gaps. Panel management relies on empanelment, the assignment of panels of patients to specific primary care providers, in order to actively review and manage patient panels. A panel manager is a staff member, usually medical assistant or nurse, who periodically checks patient panel registries to identify patients due for routine services (e.g., mammograms, colorectal cancer screening, HbA_{1c}, or low-density lipoprotein (LDL)-cholesterol laboratory work). Alternatively, the panel manager can check the health maintenance screen on the electronic medical record before a huddle or medical visit to look for these care gaps.[43] Standing orders enable panel managers to address care gaps without involving the clinician. In some practices, most routine care is complete before the clinician enters the exam room, so that visits can focus on patient concerns, issues requiring the clinician's level of expertise, treatment options, or shared care plans.

Health Coaching

Health coaches can be an important part of the medical team. Health coaching helps patients with chronic conditions by assessing the patients' knowledge and motivation, providing information and skills, and engaging patients in behavior-changing action plans likely to improve outcomes.[37] Low-income and minority patients with diabetes working with health coaches, whether they be medical assistants or other trained patients with diabetes, have been found to have better outcomes than patients without health coaches.[44] When medical assistants (MAs), nurses, health educators, or pharmacists act as health coaches, they are given protected time to take over this function.

Complex Care Management

Complex care management has been promoted as a way to address the needs of patients who are medically and psychosocially complex or are high utilizers of expensive services. Teams headed by RNs or social workers can improve care and reduce costs for complex patients who are also socially disadvantaged[45] (see Chapter 19).

BLOCK 7: CONTINUITY OF CARE

Continuity of care is associated with the triple aim: improved preventive and chronic care, greater patient and clinician experience, and lower costs.[46] Continuity requires empanelment, which links each patient to a clinician and team. Continuity from the patient perspective is measured as the percentage of patient visits with the assigned primary care provider divided by the total number of patient visits to the practice. High-performing practices measure continuity for each clinician or team, and may achieve continuity goals of 70–80%. Reaching these goals requires engagement of the front desk staff in encouraging and assisting patients to see the clinician with whom they are empaneled.

BLOCK 8: PROMPT ACCESS TO CARE

Access to care—providing care when patients need it in patient-centered and efficient ways—is closely linked

to patient satisfaction and is a prominent objective for many practices. Access is a key area for improvement in safety-net settings that typically face the challenge of high patient demand and long wait times. In a survey of 554 safety-net health centers, 68% reported lacking a process for same-day appointment scheduling.[29] Enhanced access involves providing patients with direct access to their care team during business hours, same-day appointments, extending evening and weekend clinics, and offering telephone or electronic access to the medical home during nights and weekends.[47]

BLOCK 9: COMPREHENSIVENESS AND CARE COORDINATION

Comprehensiveness is the capacity of a practice to provide most of what patients need. Care coordination is the responsibility of primary care to arrange for services that primary care is unable to provide. Care coordination involves direct communication systems with other members of the medical neighborhood, such as hospitals, pharmacies, specialists, or community organizations. In high-performing systems, clinicians automatically learn when their patients have been discharged from the hospital or specialist referrals are used to their greatest capacity when diagnostic studies are secured in advance by the primary care clinician. Improving care coordination requires teams because busy clinicians lack the time to coordinate care for every patient with every health-care institution. High-performing practices often include a care coordinator or referral coordinator with sole responsibility for care coordination. Underserved patients, who often have high rates of medical and social complexity, are especially vulnerable at times of care transitions—following hospital discharges or emergency department visits—and require close follow-up and coordination with the care team of the medical home.

Care coordination requires robust HIT systems to share medical information and communicate across the medical neighborhood. Electronic systems such as e-referral and e-consult have led to improved care coordination and communication between primary care and specialty services, especially in safety-net settings where access to specialty services for uninsured or publically insured patients is often limited.[48]

Over 40% of patients in primary care settings have behavioral health problems, and this percentage is often higher among underserved populations.[49] With the high prevalence of psychosocial complexity—housing instability, food insecurity, disability, coexisting mental illness, and substance abuse—among vulnerable populations, behavioral health integration is a core element of comprehensiveness for safety-net clinics (see Chapter 33).

Integrated behavioral health has been shown to offload work from primary care physicians, increase engagement in mental health treatment, and enhance patient satisfaction.[50,51] High-functioning practices colocate behaviorists within the medical home who partner with care teams in managing patients' psychosocial needs. Clinicians can initiate warm handoffs to behaviorists so that patients can receive mental health services the same day in the same place or obtain assistance in referrals to other community resources.

BLOCK 10: TEMPLATE OF THE FUTURE

The crown of the building blocks is the template of the future. Much has been written about the limits of the traditional 15-minute visit, especially in caring for vulnerable patients whose complex medical and psychosocial conditions require more time and teamwork.[52] Few practices have achieved this ultimate goal: a daily schedule that does not rely on the 15-minute in-person clinician visit, but offers patients e-visits, phone encounters, group appointments, or visits with other team members. Clinicians could have fewer and longer in-person visits and protected time for e-visits and phone visits. Electronic communication between patients and providers, through secure messaging and patient portals, has been shown to increase provider productivity, enhance quality, and increase patient satisfaction with care.[53,54] In a study of vulnerable patients in urban safety-net clinics, nearly three-fourths reported interest in electronic communication with their health-care providers.[55] A redesigned structure for primary care that relies on electronic, group, and team-based multidisciplinary visits along with provider visits has the potential to reduce the mismatch—greatest among vulnerable populations—between patient needs and time available.[52]

Full implementation of this future template requires payment reform that does not cover primary care only for in-person clinician visits. Some practices are receiving non-visit–based care coordination and pay-for-performance dollars on top of fee for service, payments that begin to support new modes of patient encounters. More transformative would be the elimination of fee for service altogether and instead a comprehensive risk-adjusted fee per patient with adjustments for quality and patient experience. If primary care practices can reduce unnecessary emergency department and hospital costs for their patients, these practices could also receive a portion of the cost savings.

CONCLUSION

The financing, organization, and delivery of primary care must be transformed to address the US primary care crisis. The PCMH has been widely promoted as a model for transformation. For the PCMH to sustain this momentum, substantive payment reform and

significant investment of resources is needed for primary care practices to undergo robust transformation into truly high-performing PCMH practices. Minor per-member-per-month payments and partial redesign efforts will not be sufficient to drive the level of transformation needed to improve outcomes. Payers need to see evidence that the PMCH is achieving improvements in the triple aim, including cost savings. Some recent PCMH evaluations have shown modest improvements in quality and satisfaction and mixed to neutral results on cost.[55-57] However, many of the interventions evaluated consisted of modest investments, incremental redesign, and short time frames. In contrast, evaluations of large integrated delivery systems, which underwent massive primary care transformation to achieve the PCMH model, have shown substantial improvements in quality, patient experience, and cost reduction—the triple aim.[58-61]

Primary care can be transformed—and lessons from high-functioning practices suggest that the 10 building blocks are a model to help practices in the journey toward high performance. Safety-net settings have been leaders in this transformation, which can improve quality and reduce disparities among underserved and vulnerable populations.

- The PCMH is a model for "comprehensive, continuous, patient-centered, team-based, and accessible primary care delivered in the context of a patient's family and community."[1]
- High-performing primary care practices consistently implement the 10 building blocks to achieve high-functioning medical homes.
- PCMH evaluations of high-performing systems demonstrate substantial improvements across many domains: clinical quality, utilization and access, patient experience, and reduced costs.
- The PCMH model has promise for achieving the triple aim, and reducing disparities among vulnerable populations.

Building Block	Main Elements
1. Engaged leadership	• Practice has a concrete vision with goals and objectives for transformation • Engaging frontline staff, providers, and patients in practice transformation
2. Data-driven improvement	• Robust computer-based technology • Practice-wide and team-level data on quality, access, cost, patient, and staff experience metrics tracked with specific goals and structures for improvement
3. Empanelment	• Patients assigned to specific provider and care team • Panel sizes are monitored and right-sized
4. Team-based care	• Culture shift to share the care o Stable teamlets o Colocation o Adequate staffing ratios for new roles o Standing orders and defined workflows o Defined roles with training and skills checks to reinforce these roles o Communication: team meetings, huddles, and minute-to-minute interactions
5. Patient–team partnership	• Patient-centered communication techniques: teach back, shared-decision making, motivational interviewing o Self-management support o Evidence-based care
6. Population management	• Panel management • Health coaching • Complex care management
7. Continuity of care	• Scheduling systems aligned to schedule patients to see PCP or care team • Continuity rate tracked and monitored against target
8. Prompt access to care	• Same-day appointments during weekdays • Night and weekend access with expanded hours • Phone access to care team during weekdays and after hours
9. Comprehensiveness and care coordination	• Care coordination across the medical neighborhood with specialists, hospitals, and emergency departments o With community partners o With family and caregivers
10. Template of the future: escape from the 15-minute visit	• E-visits • Telephone visits • Group visits • Visits with nurses and other team members

DISCUSSION QUESTIONS

1. Imagine that Mrs. C is your patient (or think of a socially or medically vulnerable patient you saw recently). What elements of the medical home would be most helpful to provide her with high-quality care and address her multiple vulnerabilities?
2. Reflect on a primary care practice where you currently work or have worked. What improvements would you make in the practice to achieve higher performance?
3. If a friend or family member asked you "I heard about these medical homes—is that about putting patients into nursing homes?" How would you explain what a PCMH is?
4. What are some current problems with primary care? What policy and health-care financing changes are required for primary care practices to transform into high-performing systems?

RESOURCES

Bodenheimer T, Ghorob A, Willard-Grace R, Grumbach K. The 10 building blocks of high-performing primary care. Ann Fam Med 2014;12(2):166-171.

The Safety Net Medical Home Initiative, http://www.safetynet-medicalhome.org.

Agency for Healthcare Research and Quality (AHRQ) Patient-centered medical home resource center, http://pcmh.ahrq.gov/.

Patient-Centered Medical Home, http://www.ncqa.org/Programs/Recognition/Practices/PatientCenteredMedicalHome-PCMH.aspx.

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Chapter 12

Promoting Behavior Change

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Objectives

- Describe the importance of health behavior change counseling in medical settings.
- Identify barriers and opportunities for promoting behavior change with vulnerable and underserved populations.
- Review an evidence-based and practical approach to behavior change counseling.

INTRODUCTION

> Mr. Nguyen is a 34-year-old man, Vietnamese. He lives with his girlfriend and works as a line cook. He drinks six to nine drinks several nights per week but does not meet criteria for an alcohol use disorder.

The primary goal of health care is to reduce morbidity and mortality through the prevention and treatment of disease. Health-care providers are also charged with promoting behavioral change strategies that support wellness. When thinking of causes of death, diseases such as heart disease, cancer, and respiratory disease come to mind. Underlying these causes of death, however, often lie modifiable behavioral risk factors, such as tobacco use, poor diet and physical activity, and alcohol misuse.[1] Termed "actual causes of death," these preventable behaviors account for about half of all deaths and underscore the importance of prioritizing the promotion of behavior change in health-care settings. Furthermore, psychosocial issues, such as mental illness, substance abuse, trauma, and poverty, when left unaddressed by the health-care system, can cause and exacerbate illness among the world's most vulnerable populations. Two decades of behavioral research indicate that physicians can successfully promote health behavior change in their patients.[2,3] Health-care providers who understand behavior change theory and who practice a patient-centered approach to behavior change counseling achieve the best outcomes.

MISPERCEPTIONS

When envisioning the promotion of behavior change, it is common to picture a prototypical counseling setup, which involves a series of long intervention sessions focused on specific psychosocial stressors or mental health disorders. It is no wonder that many providers choose to avoid behavior change counseling altogether, when this is their perception of what promotion of behavior change entails. Providers in medical settings typically have neither the time nor the specialty training to operate using a counseling paradigm. However, empirical evidence suggests that relatively brief interventions can have powerful effects and that a single brief empathic discussion can promote long lasting behavior change.[4] For many areas, interventions as short as 5 minutes can change important health behaviors.[5]

Another barrier to the promotion of behavior change in medical settings may be perceptions regarding who is appropriate for intervention. For example, when thinking about a patient who would benefit from behavior change around alcohol, many providers picture a patient with a

severe alcohol use disorder, many complicating psychosocial stressors, and a history of unsuccessful quit attempts. While such patients are certainly in need of services and their medical providers should address their alcohol use, they are less likely to respond to brief interventions and more likely to benefit from referral to more intensive specialty treatment. When such patients are the first, or perhaps only, to come to mind when thinking about behavior change counseling, providers may shy away from engaging patients in discussions about behavior change altogether. However, most of the behaviors our patients would benefit from changing are less intensive and more modifiable. With the case of alcohol, for example, as many as one in five patients, such as Mr. Nguyen described in the vignette earlier, may be drinking at levels that put them at risk for a range of medical and social consequences, but do not meet criteria for an alcohol use disorder. More than half of alcohol-related deaths and two-thirds of the potential life-years lost because of alcohol are among such risky drinkers. This is an example of a phenomenon known as the "prevention paradox," wherein a large number of people at small risk cause more health burden than a small number of people at greater risk.[6] These patients tend to be quite responsive to brief interventions in medical settings. Shifting one's frame of reference regarding which patients may benefit from behavior change promotion may promote implementation of such practices.

VULNERABLE AND UNDERSERVED POPULATIONS

Promoting behavior change is especially important with socially vulnerable populations. Behavioral health issues, such as sedentary lifestyle, obesity, and smoking, are more prevalent in people of lower socioeconomic position, and among certain racial and ethnic minorities.[7,8] Moreover, physicians are less likely to initiate conversations about health behavior change with lower-income patients.[9] This is the case even though low-income patients are more likely to report acting on these physician recommendations than are middle- and higher-income patients.[10]

Research suggests that health-care provider's attitudes and behavior often differ based on patient socioeconomic status (SES) and ethnic minority status. Providers tend to spend less time, use fewer rapport building statements, speak more quickly, and demonstrate more verbally dominant behavior with ethnic minority patients compared with white patients.[11] When working with lower SES patients, providers are also more directive, less collaborative, are less likely to use partnership building statements, and are less likely to initiate conversations about behavior change.[9,12] These differences in communication may be due to provider's attitudes. Providers have reported less trusting attitudes toward ethnic minority patients, viewing patients of lower SES and/or ethnic minority status as less intelligent, more likely to abuse substances, lacking self-control, and having less desire to be physically active.[13,14] Differences in provider's attitudes and behaviors toward ethnic minority and lower SES patients undoubtedly have an impact on engagement, which in turn can affect important patient outcomes. Compounding this issue, ethnic minority patients report less trust in physicians and the medical system compared with white patients.[11,15,16] This is important because patient trust is associated with treatment adherence and improved health.[17,18]

MOTIVATIONAL INTERVIEWING

Motivational interviewing is style of communication that can be used by health-care providers to strengthen a patient's own motivation and commitment to change.[19] Motivational interviewing is a collaborative, goal-oriented approach, which encourages providers to pay particular attention to patients' language regarding change. It has been applied to a range of health behaviors, including medication adherence (in HIV, cardiovascular disease, diabetes, contraception), treatment engagement (continuous positive airway pressure [CPAP] use, group participation, diabetes self-management, prenatal care), screening compliance (mammography, sexually transmitted disease, colorectal cancer), and lifestyle management (diet, physical activity, safe sex).[20] Motivational interviewing has been found to be effective cross-culturally and may even differentially benefit ethnic minority patients.[21]

In this chapter, we explore four processes inherent to motivational interviewing and how they may be applied to promote behavior change with vulnerable and underserved populations. The four processes include engaging, focusing, evoking, and planning for behavior change (see Box 12-1). We provide a brief description of each process,

Box 12-1. The Four Processes of Motivational Interviewing

Motivational Interviewing Process	Description
Engaging	Developing a trusting, respectful, working relationship
Focusing	Collaboratively identifying an area of behavior change to explore
Evoking	Strategically drawing out patient's own motivations or reasons to change
Planning	Collaboratively outlining the details regarding how change will occur

as it relates to the promotion of behavior change among vulnerable populations and provide practical strategies for effectively counseling patients in each process.

ENGAGING THE PATIENT

The first step in promoting behavior change involves the development of a good patient–provider relationship. Forming a meaningful connection with patients is a necessary precursor to focused behavior change work and remains of central importance throughout the course of the working relationship. Humanistic theory asserts that people are naturally driven to seek health and happiness. Three conditions in therapeutic relationships are necessary to enhance this powerful inner drive toward health: warmth, accurate understanding of the person by the helper, and unconditional positive regard.[22]

Empirical research also underscores the importance of engaging the patient. A recent meta-analysis of randomized controlled trials evaluating the impact of the patient–provider relationship on validated medical outcomes found a significant positive effect across 13 trials, and the magnitude of the observed effect was nearly double the effect of aspirin in reducing myocardial infarction.[23]

The costs of failed engagement in promoting behavior change are high. While a range of patient and systems level factors can impact engagement, provider behavior plays a key role. Poor engagement can lead to treatment dropout, poor treatment compliance or medication nonadherence, and failure to make healthy choices for a variety of medical conditions. The issue of engagement may be particularly important for vulnerable populations, for whom both provider and patient behaviors can present barriers to a mutually trusting and respectful relationship.

STRATEGIES FOR ENGAGEMENT

While we are often focused on the role of the patient in the development of engagement, the provider's communication style can significantly impact the development of engagement. A number of studies have found that patients are more likely to trust providers who are collaborative, comforting, listen carefully, and explore patient experience of disease and illness.[24-27] A recent meta-analyses examining the relationship between physician communication and treatment adherence found that a communication style which included empathy and rapport building resulted in greater treatment adherence.[28] In sum, a collaborative and empathic communication style is key to developing relationships that increase the likelihood of health behavior change, especially in ethnic minority and lower SES populations. In the following subsections, we focus on several concrete strategies that can be used by providers, even in busy clinic settings, to promote engagement.

Being Present and Mindful

In busy clinic settings, it can be a challenge to be present and mindful with each patient. When working with vulnerable populations, it can be hard to avoid ruminative thinking about challenging patients or barriers to effective care. When pressed with the daunting task of caring for those who are in such great need, it can be easy to neglect important self-care activities. In medicine, mindfulness is the purposeful and nonjudgmental attention to one's own experiences, thoughts, and feelings.[29] Physician mindfulness has been found to improve patient care and is associated with better rapport building, increased discussion of psychosocial issues, and higher patient satisfaction. Mindfulness has also been found to improve practitioner's well-being, stress levels, and burnout.[30,31] Several simple strategies may be used to promote mindfulness with patients (see Box 12-2).

Empathy and Reflective Listening

Empathy is a construct that is often discussed as a critical clinical skill for health-care providers to promote client engagement. Some ambiguity surrounds the term "empathy," with interpretations ranging from the ability to share the feelings of another to general warm or caring personality traits. In health-care communication, one helpful way to think of empathy is the extent to which the clinician makes an effort to understand the unique perspective of the patient.[19]

Frequent and accurate use of reflections, or statements that paraphrase or infer the underlying meaning of what a client has said, is the primary means by which we operationalize empathy. In health-care settings, provider's empathy has been found to be predictive of patient outcome across a range of issues. For example, in one correlational study of patients with diabetes treated by family physicians, physicians' scores on a self-report scale of empathy were highly predictive of patient control of hemoglobin A_{1c} and low-density lipoprotein.[32] Provider's empathy has also been found to be related to outcomes in depression,[33] cancer,[34] and the common cold.[35]

Box 12-2. Strategies to Promote Mindfulness

- Taking a moment before each patient to examine thoughts and feelings (e.g., "It's late in the day; I don't know if I have any energy left")
- Maintaining a healthy work–life balance
- Seeking formal or informal support from professional mentors and peers
- Purposefully seeking to identify explicit and implicit biases that may impact care. One interesting way of exploring implicit biases can be found at https://implicit.harvard.edu/implicit/

Motivational interviewing provides us with guidance on how to empathically listen to our patients using the skill of reflection. During the engagement process, we should rely heavily on the use of reflective listening. Taking the time to understand our patients' unique situations and perspectives promotes trust and alliance. Reflective listening can also help us ensure accurate understanding, which may be particularly important for vulnerable populations whose cultural and experiential background may differ significantly from the provider, leading to misinterpretation.

With reflective listening, providers are essentially making guesses about what patients mean by what they say. However, instead of stating the guess in the form of a question, communication is streamlined by transforming the hypothesis into a declarative statement with a downward inflection at the end. Box 12-3 provides several examples. As can be seen, there are often multiple possible meanings underlying what a patient has said, and a provider will use his or her understanding of the patient's individual circumstances and strategic aims to determine what aspect of what the patient has said might be most helpful to reflect. When conducting motivational interviewing, providers are encouraged to use at least two reflections for every question that they ask.

Box 12-3. Examples of Reflective Listening

Mrs. Fernandez is a 62-year-old woman. She does not work and lives with her adult nephew. She is conversant in English and has poorly controlled Type 2 diabetes

Patient Statement

"My sugars are probably off the charts."

Provider Guess About Meaning	Reflection
Do you mean that you are concerned about what you ate for breakfast?	You are concerned about what you ate for breakfast.
Do you mean that you haven't been checking your sugars lately?	You haven't been checking your sugars lately.

Mr. Jones is a 55-year-old man. He lives with his partner and receives disability. He is HIV+ and struggles with medication adherence and depression.

Patient Statement

"I haven't missed one single dose since our last visit."

Provider Guess About Meaning	Reflection
Do you mean you've been using some of the strategies we discussed?	You've been using some of the strategies we discussed
Do you mean your labs last month really scared you?	Your labs last month really scared you.

Box 12-4. Examples of Values Exploration Questions to Promote Engagement

"Tell me what matters most to you in life?"

"What are some of the most important values that guide your life?"

"How do you hope your life will look a few a years from now?"

"Tell me about your family? How old are your children? What are they doing right now?"

Values Exploration

Another strategy for promoting engagement involves taking time to ask about and understand the patients' goals and values.[19] This may involve briefly talking about life activities and relationships important to the patient. Not only do such conversations build rapport, they simultaneously increase patients' motivation to change by giving them a chance to verbalize the healthy ideals that are important to them. One simple method for understanding the motivators that drive your patients is by asking them open-ended questions and then listening empathically using the skills of reflection. Examples of values questions adapted from Miller and Rollnick[19] can be found in Box 12-4.

Responding to Discord

Even when we invest in efforts to engage with patients, discord or disharmony in the collaborative relationship may still arise.[19] Discord often takes the form of a "fight or flight" response on the part of the patient. This may involve taking an oppositional stance ("You'd never be able to understand what this is like.") or disengagement from the interaction. Discord can often be perceived as wrestling with the patient, versus the perception of dancing that is often experienced when collaboration is high.

In motivational interviewing, relationship discord is distinguished from the expression of reasons not to change or barriers to change (e.g., "Drinking helps to ease my anxiety."). Such counter-change talk is more indicative of underlying ambivalence about change versus problems with the interpersonal relationship. The section "Evoking from the Patient" provides guidance on responding to language about reasons or barriers to change. When it comes to discord, however, several strategies are available. First, engaging in active listening using reflection to understand and explore patient discord is often sufficient to extinguish it. Similarly, clinicians could validate and apologize for any missteps perceived by the patient, shift focus to another topic, emphasize the patient's choice or

autonomy, or return to earlier processes to determine whether they inadvertently or prematurely moved into a later process, such as focusing, evoking, or planning.

FOCUSING WITH THE PATIENT

A good working relationship leaves providers and patients with the groundwork they need to identify and pursue a specific direction. This focusing is the second process in motivational interviewing. Developing clear and collaboratively generated goals or areas for exploration allows for purposeful interactions aimed at promoting behavioral change. Interactions without focus are less likely to lead to behavioral change.

There are several potential sources of focus in medical interactions.[19] In many circumstances, the patient will present with a problem or concern that becomes the area of focus (e.g., "I'd like to quit smoking."). Other times, the setting itself will determine the direction of an interaction (e.g., an HIV testing and counseling center). Finally, the medical provider may be a source of focus (e.g., a physician is concerned about the diabetes self-management practices of a patient with poorly controlled blood sugar).

In motivational interviewing and other patient-centered approaches, providers are encouraged to find direction collaboratively by using a guiding style that actively integrates all potential sources of focus. In situations in which direction is clear, focusing may simply involve confirming the goal of one's work with a patient. However, in other cases, direction may be unclear or there may be many competing priorities to choose from, in which case specific focusing skills will be called into play.

Focusing skills become even more important with vulnerable populations as providers seek to efficiently identify areas of greatest need. Even with an average patient panel, a provider could easily spend all of his or her time with a patient assessing and intervening to promote behavioral change.[36] This problem may be magnified with vulnerable populations in which prevalence of behavioral risk factors is increased. Good focusing skills will help the provider to collaboratively identify potential areas of behavioral change that can be manageably addressed in their specific context. In addition, as Maslow described, human needs can be thought of existing in a hierarchy, and our motivation to achieve a given need is contingent on satisfaction of more basic needs.[37] Providers working with patients whose physiological and safety needs are not being met because of hunger, poverty, violence, or other factors should be mindful of these larger contextual issues in their patients' lives. If available, teaming up with allied health professionals, such as social workers, to help patients address structural barriers in their lives, may help increase their chances of successfully focusing on other behavioral health issues.

STRATEGIES FOR FOCUSING

The goal of focusing is, for the clinician and patient to agree on a behavioral topic for discussion. Medical providers have the difficult task of balancing the many medical and behavioral needs of the patient within a small time window. On the provider's part, some clinical judgment is required to triage presenting issues and delegate time accordingly. With some acute issues, it may not be feasible or appropriate to address behavioral issues at all, and all of the provider's efforts may be spent on medical procedures. In contrast, with some high-risk behaviors (e.g., needle sharing), it may be appropriate to minimally address medical issues, and focus primarily on the pressing behavioral health issue. For most patients, though, particularly in outpatient continuity settings, it will be clinically appropriate to address both.

Asking Permission

One strategy that sets a respectful tone for focusing is asking permission. Asking permission implicitly communicates support of the patient's autonomy and may increase buy-in and active participation in the interaction. For example, a provider might ask: "Would it be alright if we spend a few minutes talking about contraception?" Of course, providers should not ask permission if they are not able or willing to accept no for an answer.

Normalizing

In circumstances in which an area of focus involves a stigmatized behavior, normalizing the focus may increase patients' willingness to disclose. For example, "I like to check in with all of my patients about safety. Do you feel safe at home?"

Agenda Setting

Agenda setting is a strategy for collaboratively and explicitly mapping out what will occur during an interaction. For example, a provider might ask a patient for permission to spend the last few minutes of a visit discussing lifestyle changes that the patient is contemplating. Training providers in agenda setting techniques has been shown to improve patient satisfaction.[38]

Providing a Menu of Options

Another strategy for focusing involves providing patients with a menu of potential health behavior topics to discuss. The menu could be sought from the patient himself (e.g., "What behavior changes have you thought about making?") or it can be generated by the provider. Menus of options could be presented verbally, or using a visual aid. A menu gives patients the freedom to identify those lifestyle topics of greatest importance to them: "If you were to pick one issue to discuss today, which would it be?" The menu also may help patients not yet contemplating health

Box 12-5. Collaboratively Sharing Using Elicit–Provide–Elicit

Mrs. Dodd is a 63-year-old woman with poorly controlled asthma. She has presented to the emergency department three times in the past year and has had poor adherence to preventive medication.

Provider (elicits what patient knows): "What's your understanding of how things have been going in terms of controlling your asthma?"

Patient: "I know things have been pretty out of control. My rescue inhaler doesn't seem to be enough anymore. But I've heard that steroids are dangerous to take all the time."

Provider (provides): "Your recent visit to the emergency room and what you've reported about your ability to control your breathing are concerning to me. It's true that for a very small number of people, steroids can have harmful side effects. But the risk of damaging your lungs from repeated asthma attacks is much larger than the risk of potential side effects from the steroid."

Provider (elicits reaction): "What do you make of that?"

Patient: "Really? I didn't know that. I thought it was just discomfort. I think I'm ready to discuss some of the steroid options."

behavior change to choose a topic they can at least discuss in a hypothetical way ("If you were to some day make a healthy change, in which area might that be?").

Collaboratively Sharing Information or Feedback

Providing patients with information and feedback is an effective tool to promote focusing. For example, educating a patient about safe drinking limits may lead to a focus on risky drinking behavior. Similarly, providing a patient with feedback about her HbA_{1c} level may lead to a focus on diabetes self-management practices.

The Elicit–Provide–Elicit technique is one strategy for sharing information and feedback in a collaborative style.[39] Using this technique, the provider first elicits what the patient knows or thinks about a topic. If necessary, information can then be provided in a way that is tailored to what the patient already knows. Finally, the provider can elicit what the patient thinks of the information or how, if at all, it impacts her thinking about her health behavior. Consider the example in Box 12-5.

EVOKING FROM THE PATIENT

Once a trusting working relationship has been established and a collaborative focus has been achieved, providers should draw out and strengthen the patient's own motivations to change through the process of evoking.[19] Evoking is a strategic response to patient ambivalence. For example, a patient considering colorectal cancer screening may, on the one hand, have a fear of developing cancer, want to live a long and healthy life, and value what his medical providers recommend. On the other hand, he may feel very uncomfortable about receiving a colonoscopy, fear that it will be painful or embarrassing, and at times discount the probability that he himself could get cancer.

While providers are encouraged to acknowledge and accept the side of the patient's ambivalence that does not favor change, when evoking, providers are called upon to differentially focus their clinical efforts on the side of the patient's ambivalence that favors change. Process research suggests that provider behaviors consistent with a motivational interviewing approach increase the amount that patients talk about reasons for change, and that this patient language in turn predicts outcomes.[40]

It should be noted that the evoking process is only appropriate in situations in which there is clearly a healthy behavior change to be made (e.g., substance misuse, treatment noncompliance, unprotected sex).[19] For other issues that do not have a clear direction in which to seek resolution of ambivalence (e.g., organ donation, divorce), providers may seek to maintain neutrality and not influence the direction of change. Some issues (breastfeeding, resuscitation orders) are more nuanced and will require consideration of contextual and other factors to make a determination regarding the appropriateness of evoking.

STRATEGIES FOR EVOKING

Recognizing Change Talk

"Change talk" is a term that refers to patient statements made in favor of change. Categories of change talk include a desire to change, readiness to change, and the ability to change. However, the ultimate in change talk is "commitment language," which is a strong signal that behavior change will soon occur.[41] It is often easy to miss "change talk" in the midst of "counter-change" talk (Box 12-6).

Box 12-6. Change Talk

Mr. Jones, the aforementioned 55-year-old man living with HIV.

Mr. Jones: "Taking my medications just reminds me that I'm sick. I want to suppress the virus, but sometimes I think the pills are worse than the disease."

Provider: As providers, it is easy to focus on the counter-change talk in the statement above. However, there is an element of change talk in this statement: "I want to suppress the virus..."

Recognizing change talk when it happens will allow providers to respond to it in an evoking fashion.

Box 12-7. Responding to Change Talk

Mr. Jones: "I want to suppress the virus…"

Open-ended question	"Why do you want to suppress the virus?" "What would it be like for you to have an undetectable viral load again?"
Affirmation	"You're a real fighter when it comes to your health."
Reflection	"You want to see your viral load start going back down again."

Responding to Change Talk

When change talk does occur, providers seeking to promote behavior change through evocation should seek to differentially respond the change talk. Providers can use core communications skills such as open-ended questions, affirmation, and reflections to highlight the change talk that the patient has said. Box 12-7 provides examples based on the aforementioned change talk from John.

Evoking Change Talk

Providers can explicitly draw out change talk from a patient by implementing several strategies. One obvious strategy is to ask open-ended question, the answer to which is change talk. Such questions allow patients to develop their own arguments for change, which is more powerful than having providers tell them why they should change. Several examples of evocative questions can be found in Box 12-8 below.

Ruler Exercises

There are also several structured activities specifically designed to draw out change talk. One such activity is the use of a scaling ruler, which can be implemented in very brief interactions to elicit change talk. The purpose of the ruler exercise is not actually to assess readiness to change, but to give patients an opportunity to make their own arguments for change. Box 12-9 provides examples of how to use ruler exercises in the evocation process.

Box 12-8. Evocative Questions to Evoke Change Talk

"What are some good things that could happen if you cut down on your drinking?"

"What are some strengths and resources you could draw on if you decided to exercise more?"

"Why wouldn't you want to have to go on insulin?"

"What scares you about your blood pressure?"

"What strategies helped you to quit before?"

"What would it be like to not have to smoke to manage your anxiety … to be free of cigarettes … to really know that you know how to quit and stay quit."

"How would you like your viral load to look in 6 months?"

Box 12-9. Using Rulers to Explore Importance and Confidence

1. "I'd like to understand how important it is to you personally to change your _____ (make the change under discussion). If 0 is not important and 10 is very important, what number would you give yourself today?"
2. "Why did you give it a _____ (number the patient gave) of a _____ (lower number than the patient gave)?" This elicits change talk. ("I gave it a 7 and not a 3, because I'm afraid of cancer.")
3. "What would it take for you to give it a _____ (higher number than the patient gave)?" The answer to this question tells the provider what specific medical information might serve to increase the patient's importance, either by increasing her or his concern or removing barriers.

1. "If you were to decide to (make the change under discussion), how confident are you that you would be successful, if 0 is not at all confident and 10 is very confident?" This tells the provider the patient's confidence level relative to importance. Some providers then try to raise whichever metric is lower.
2. "Why did you give it a (number the patient gave it) and not a (lower number than the patient gave)?" The answer to this question promotes "change talk" and may help identify the patient's strengths. ("I know I can quit drinking if I put my mind to it, because I have already quit smoking.")
3. "What would it take for you to give it a (higher number than the patient gave)?" This identifies barriers to change that both provider and patient can now collaboratively address.

PLANNING WITH THE PATIENT

When readiness to change is sufficiently high, moving into the planning process is appropriate. During planning, providers and patients collaboratively generate the details regarding how change will occur. Effective planning usually addresses the "who, what, where, when, and hows" of change. In some cases, planning may involve patients committing to making small lifestyle changes on their own, and in other circumstances it may involve referral to services to more fully address a problem.

STRATEGIES FOR PLANNING

The first step in the planning process involves accurately judging whether a transition to this process is appropriate

in the first place. As providers, it can feel uncomfortable to leave an interaction without developing a plan for change. While this desire for planning comes from a good place on the part of the provider, prematurely planning can provoke resistance. The flavor of this resistance varies with patients' cultures (e.g., arguing against the need for change, passive smiling, silence, changing the topic, passive compliance), but is universally unpleasant: rapport is damaged and patients resist. It takes time for patients to navigate the earlier stages of the change process. Many providers have experienced patients who finally take action after years of thinking and talking about change. Their thinking and talking represent indispensable preparation and premature planning could, in fact, have prevented such progress.

Readiness to plan can be assessed by listening for the amount and strength of patient change talk in relation to counter-change talk. Providers who believe that a transition to planning is appropriate may choose to test the waters by explicitly asking patients. As with any process in promoting behavior change, be prepared to revisit earlier processes if readiness changes during an interaction.

Know Available Resources

Once readiness to plan has occurred, it is helpful as a provider to know what resources are available to patients. It can be helpful to identify and catalog of community-based and Internet resources that can help patients to achieve their behavioral goals.[42] Examples of community-based resources include toll-free "quit smoking" lines; exercise programs sponsored by departments of public parks and recreation; and other programs sponsored by nonprofit organizations such as the YMCA and disease-specific advocacy groups (e.g., local chapters of the American Diabetes Association). Similarly, many evidence-based materials are available that include self-help strategies for a variety of health behaviors. In addition, with an increased emphasis on behavioral health in medical settings, many programs offer colocated or fully integrated behavioral health services.

Understanding the Basics of Specialty Care

For patients with more extensive behavioral health issues, specialty treatment may be appropriate. Knowing which behavioral health issues are appropriate for brief intervention in medical settings and which likely necessitate more extensive clinician contact is paramount. For example, while there is good evidence to suggest that risky alcohol use is often responsive to brief intervention in primary care,[5] risky drug use is less responsive and likely requires specialty treatment.[43] Specialty intervention skills can be learned and applied by medical providers themselves in certain circumstances. However, trained behavioral health providers can often spend more time with patients and have received extensive training on promoting behavioral change. Either way, a basic level of familiarity with commonly used approaches can be helpful in presenting patients with treatment options.

Many behavioral health specialists use an approach similar to the four motivational interviewing processes described in this chapter. However, behavioral health specialists have typically also received extensive training in skills-based approaches that allow them to help patients tackle behaviors for which basic planning is not enough. For example, Mr. Jones, the African-American patient living with HIV and depression, may be sufficiently ready to address his depression, but collaborative planning between him and his medical provider has not proven sufficient to increase his medical adherence and help him engage in other strategies to reduce his feelings of depression. In this case, specialty care may be appropriate.

One commonly used form of specialty care that patients in medical settings are referred to in the planning process is cognitive behavioral therapy (CBT). CBT is based on learning theory and emphasizes the relationships between thoughts, feelings, and behaviors. CBT teaches patients to identify and challenge negative thoughts that influence maladaptive or unhealthy behaviors. For example, Mr. Jones may have negative beliefs such as "I'll always be depressed so why bother taking my medications" or "I don't deserve to get any pleasure out of life." These beliefs could influence Mr. John's engagement in behaviors that lead to a poorer quality of life (i.e., poor medication adherence, increasing social isolation). By learning to recognize and challenge these types of beliefs, patients are less likely to engage in behaviors that could decrease quality of life. CBT also helps patients to set small, realistic goals to improve behavioral health and encourages using small rewards for meeting goals. For example, Mr. Jones could seek to take and record his medication for a week-long period, and plan to reward himself with his favorite ice cream if he succeeds. The primary function of CBT is to help patients change their thoughts and behaviors surrounding a particular behavioral health problem.

CBT has been useful in managing myriad behavioral health concerns. It is particularly helpful during the planning process, when patients have high levels of readiness to address an issue. A recent review of CBT for chronic pain found that patients who received a CBT intervention reported improvements in pain, disability, and mood.[44] Similarly, CBT studies on patients with diabetes resulted in improvements in HbA_{1c} levels, diabetes-related distress, blood glucose testing, and problem-solving skills.[45] Current clinical practice guidelines include CBT to aid in smoking cessation.[46] Finally, several reviews on weight management have emphasized the importance of cognitive behavioral approaches to weight loss.[47,48]

Acceptance and commitment therapy (ACT) is another skills-based approach that is frequently implemented with patients who are managing behavioral health concerns. ACT is based on the idea that experiencing a wide range of thoughts and emotions is normal. However, problems occur when we are unwilling to experience unpleasant thoughts and emotions, and then engage in behaviors to avoid such experiences, often at the expense of one's values. ACT teaches patients to be mindful and accepting of such experiences, reduce the control that distressing thoughts and feelings can have on one's behavior, and increase value-consistent behaviors. This process, known as psychological flexibility, is defined as "being able to be present in the moment, fully aware and open to our experience, and to take action consistent with our values."[49]

ACT has been used to address a number of health concerns such as chronic pain, diabetes, weight loss, and smoking cessation. ACT has been most thoroughly studied with chronic pain patients. Six randomized controlled trials have demonstrated improvement in chronic pain management when using ACT. Patients receiving ACT report decreased pain, related medical appointments, and improvements in functioning.[50] ACT has also been shown to be useful with patients with diabetes. A randomized controlled trial demonstrated improvements in diabetes self-care and HbA_{1c} levels when patients received an ACT intervention.[51] Finally, a number of smaller pilot studies lend support to an ACT model of care for improving diet, increasing physical activity, and smoking cessation.[52-56]

COLLABORATIVE REFERRAL AND SKILL EXCHANGE

When sharing referral information or skills with patients, it is helpful to continue using collaborative processes, and avoid taking a top-down stance (Box 12-10). Asking permission and drawing on the expertise of the patient can be invaluable in this process.

Box 12-10. Example of Collaborative Planning

Ms. Kirk is a 44-year-old female with mild hypertension and recurrent bronchitis. She has been a lifetime smoker who is interested in quitting.

"What's your understanding of ways in which a behavioral health specialist might be able to help you with your goal of quitting smoking?"

"Because you already know how to quit, I am wondering if we could work on a plan together that would focus on how to stay quit even when you experience cravings. What ideas do you have?"

Box 12-11. Planning with Elicit–Provide–Elicit

Provider elicits what patient knows: "What ideas do you have for strategies for cutting down?"

Patient: "I think just knowing the limit will help. I'll keep track of my drinks and try not to have more than four."

Provider gives more information: "Setting specific goals and keeping track are excellent strategies. Some people have also found that switching between alcoholic and non-alcoholic drinks can be helpful. As can practicing how to say no when you decide you don't want a drink."

Provider elicits reaction: "What do you think of those strategies?"

Patient: "Alternating might help. That way I can still stay and hang out. I don't think I'd have a problem saying no if I didn't want a drink."

While patients are typically able to generate their own plans for change, there are some circumstances when it is appropriate to share information or resources. Imagine Mrs. Fernandez, the obese, diabetic patient described earlier, has decided to improve her diet. It may be appropriate to refer this patient to an online resource that discusses healthy eating. Similarly, Mr. John could be given medication adherence tips, such as pairing his medication taking with another routine activity, like brushing his teeth. When sharing information or resources, the Elicit–Provide–Elicit technique can be a valuable tool. Consider Mr. Nguyen, the risky alcoholic patient described earlier (Box 12-11).

Addressing Barriers

While the evocation process encourages us to focus on reasons for change, once ambivalence has been resolved and patients are reading to plan, it may be appropriate to draw out potential barriers to change so that they can be addressed. This could be done in an open-ended fashion: "What would your life be like if you made that change today? What would be missing….?" or providers could offer and explore obstacles they anticipate based on their clinical expertise. Once barriers are identified, using a collaborative approach to troubleshoot them is ideal. Often, patients themselves have the most appropriate and feasible solutions to barriers. As described earlier, using a systems-based approach and integrating services of behavioral health and other allied health professionals can also allow providers to offer more intensive services to patients with extensive barriers.

Another potential barrier to behavioral change may be health literacy. Health literacy is the ability to access and understand important health information (see Chapter 15). While health literacy is important throughout all processes

involved in promoting behavior change, it is even more important during the planning stage, during which providers often share and exchange health information. It is important to be mindful of health literacy issues when developing and sharing resources with patients. In addition, taking a patient-centered, collaborative approach, including strategies such as Elicit–Provide–Elicit, can help prevent ineffective information exchange.

Summary and Follow-up

Clinic systems also can assist patients in following through on behavioral action plans. One simple strategy that can be implemented within a patient visit is asking patients to summarize the change plans they have made. Writing down change plans (also known as action plans) can increase the chances that a patient will follow through. Documenting behavior counseling discussions and action plans in medical records may serve as a cue to follow-up. It also makes other members of the health-care team aware of a patient's behavioral goals. Health-care providers can also support patients in achieving their goals by proactively following up with patients between visits to assess progress and help troubleshoot barriers to implementing an action plan.[57]

OTHER MODELS

5AS MODEL

In addition to motivational interviewing, several other models are available to guide providers in promoting behavioral change. For example, the 5As model, which was originally developed to promote smoking cessation but has been more recently applied to other behavioral health issues such as obesity, provides an overarching framework for behavior change counseling. The 5As, described in Box 12-12, provide practical, action-oriented steps for identifying and intervening around behavioral health issues.

Box 12-12. Brief Overview of Other Behavior Change Promotion Models

The 5As

Ask: about health behavior

Advise: health behavior change

Assess: willingness to change

Assist: provide skills, medications, or referrals

Arrange: follow-up

SBIRT

Screening: determine the severity of the problem

Brief intervention: increase motivation for change or plan for change

Referral to treatment: provide access to specialty care for those needing more extensive services

The 5As framework provides less guidance about the interpersonal style in which each step should be conducted and, consequently, such an approach could have low or high consistency with the motivational interviewing approach described earlier, depending on the style of intervention. For example, asking about health behavior could take place before or after the development of engagement, advice could occur with or without permission, and assistance could be given in a top-down or collaborative and evoking fashion.

SCREENING, BRIEF INTERVENTION, AND REFERRAL TO TREATMENT

The screening, brief intervention, and referral to treatment (SBIRT) is an approach designed to quickly assess the severity of substance use, provide brief intervention to risky users, and refer those requiring more extensive services to specialty treatment. Like the 5As, SBIRT could be conducted in a fashion that is highly consistent or highly inconsistent with motivational interviewing. In fact, the most commonly implemented SBIRT protocol, developed by the National Institute on Alcohol Abuse and Alcoholism (2005),[58] has elements of both. The degree of motivational interviewing underlying an SBIRT protocol has been cited as a potential moderator of treatment effect that has not been adequately described in treatment outcome reports.[59]

CONCLUSION

Promotion of behavior change is integral to the practice of medicine, particularly with vulnerable populations, who often have higher rates of unhealthy behaviors. Modifiable behavioral risk factors are the leading actual causes of death; differentially affect vulnerable populations, and merit attention from health-care providers. Providers can have a significant impact on health behaviors with brief interventions, particularly if they employ patient-centered practices consistent with a motivational interviewing approach. Such patient-centered approaches may be especially important with lower SES and ethnic minority patients, who are less likely to be approached with a collaborative style. In this chapter, we discussed practical strategies for engaging patients, a process that is necessary to effectively promote behavior change. We highlighted several strategies collaborating with patients to identify the best targets of behavior change counseling. For behavior changes in which there is a clearly healthier choice, providers seek to evoke, or draw out the patient's own motivations to change. This is done by listening for the change talk in what patients say and strategically responding to it, or by asking questions or doing structured activities designed to draw

out change talk. Finally, when patients are sufficiently ready, a collaborative plan for change can be made. CBT and ACT principles can be integrated into the planning process. Using the patient-centered techniques of motivational interviewing allows clinicians to effectively support their patients in making changes in their behavior to improve and protect health.

Behavior Change Counseling

- **Engage the Patient**
  Ask about your patients' health-related goals and values.
  Actively listen using reflections.
  Use discord as feedback to respond differently.
- **Focus with the Patient**
  Collaboratively set agenda
  Ask permission, normalize, or use a menu of options to introduce your own focus
  Use Elicit–Provide–Elicit to provide feedback intended to promote focus (e.g., lab results)
- **Evoke Change Talk**
  Recognize motivational speech when you see it.
  Respond to change talk with reflections, summaries, or open questions that ask for elaboration.
  Draw out change talk using readiness, importance, and confidence rulers (Why are you not a lower number?)
- **Plan When Appropriate**
  Only plan when patients are ready to change
  Draw out the patient's own ideas about how change should occur
  Use Elicit–Provide–Elicit to share resources and skills

Source: Adapted from Miller WR, Rollnick S. Motivational Interviewing: Helping People Change, 3rd ed. New York: Guilford Press, 2013.

DISCUSSION QUESTIONS

1. "Dancing versus wrestling" can be a useful metaphor for behavior change counseling. "Wrestling" ends with a winner and a loser (or two losers!). "Dancing" means the provider is guiding the conversation while the patient is doing most of the talking. Think back to a recent patient with whom you danced and another with whom you wrestled. What do you think you may have done that led you to dance with one and wrestle with the other?
2. Think back to a healthy behavior change that you made some time in the past. Did you perceive making the change as important for your health? Why? What are some evocative questions that could have led you to argue for making the change?
3. Think about the last time you tried to help a patient or someone else in your life plan a change. In retrospect, was the person ready? What pieces of information help you decide when a patient is ready?

RESOURCES

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Chapter 13

Assessing and Promoting Medication Adherence

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Objectives

- Define medication adherence.
- Describe the scope and consequences of poor medication adherence.
- Summarize the patient, clinician, and system factors that contribute to poor medication adherence.
- Describe clinician–patient communication strategies to assess and promote medication adherence.
- Identify interventions to promote medication adherence.

INTRODUCTION

Mr. Cruise is a 55-year-old janitor who left his job 1 year ago because of worsening heart failure, hypertension, and diabetes. He manages to keep his regular appointments with his cardiologist and primary care physician, but over the past year, he has been hospitalized four times for management of his heart failure. During each hospitalization, his medical team suspects poor adherence with his medication regimen.

Patients living with chronic disease (e.g., hypertension, diabetes, or HIV) often have complex treatment regimens and use multiple medications. Patients may find that being adherent with medications is a challenge, and poor medication adherence makes it difficult to achieve the desired goals of chronic disease management.

The World Health Organization (WHO) defines adherence as "the extent to which a person's behavior—taking medications, following a diet, and/or executing lifestyle changes—corresponds to agreed recommendations from a health care provider."[1] Many factors influence an individual's ability to adhere to medication instructions and agreed upon life-style behavioral changes required to manage chronic disease. Medication adherence is an essential element to achieving positive therapy outcomes. Therefore, strategies focused on improving adherence should also strengthen the collaboration between patients, family members, caregivers, and clinicians and mitigate patient, clinician, and system barriers to adherence.

This chapter describes the problem of poor medication adherence, and explores patient, clinician, and system factors that contribute to poor adherence. It provides communication strategies designed to identify factors that result in poor adherence, clarify the causes of poor adherence, and promote higher levels of adherence.

SCOPE OF THE PROBLEM

Mr. Cruise's clinical picture is complex and his responses to his medication regimen are unexpectedly poor. He has had frequent hospitalizations for his chronic illnesses, and few of his medications seem to be working as predicted.

Poor medication adherence is a worldwide problem and the problem is growing as the burden of chronic disease is growing.[1] Studies suggest that as many as half of medical patients do not completely follow the treatment recommendations of their clinicians in developed countries such as the United States; the rates are often much lower in developing countries in Africa and Asia.[1,2] Poor adherence is of particular concern among those with multiple chronic medical problems, such as HIV, hypertension, and diabetes,[3,4] as well as among lower-income patients who face many barriers to adherence, including access to medications and rising medication costs.[5] In resource-poor countries such as Africa, patients on antiretroviral therapy experience barriers to adherence that include food insecurity and transportation costs.[6]

The consequences of poor adherence can be devastating. Over 100,000 deaths annually in the United States have been attributed to poor adherence with medication regimens.[7] Poor medication adherence also leads to higher rates of hospitalizations, emergency room visits, and outpatient visits, as well as worsening health status.[2,8] In addition to adverse health consequences and potential financial waste, poor adherence can lead to frustration for both patients and clinicians and thus may contribute to the breakdown in this relationship and mistrust of the health-care system.

FACTORS ASSOCIATED WITH POOR ADHERENCE

ISSUES AT THE INTERFACE OF PATIENT AND TREATMENT

> Mr. Cruise takes nine different medications: six for management of his heart disease and three for his diabetes. Since leaving his job, he has experienced severe financial strain and now suffers from depression.

Patients may experience many factors that can have an impact on their ability to properly take medications. These factors include, but are not limited to access, low resources, lack of social support, mental illness, health beliefs, substance abuse, mistrust of the health-care system, negative personal interactions with clinicians, fear, and lack of understanding of disease and medications. Patients may believe that they are adherent to medications because they take a medication every day, when in fact how the patient takes the medication may be incorrect. It is important when assessing medication adherence that providers ask the patients, "tell me how you take this medication." There are multiple reasons that patients choose not to follow the advice of their health-care providers, particularly when complex medication regimens or side effects conflict with the patient's personal identity or goals.[9] Understanding the elements at the interface of patient and treatment may contribute to better assessment and management of poor adherence.

INTERACTING DIMENSIONS THAT IMPACT ADHERENCE

The WHO describes five dimensions that affect adherence: (1) therapy related, (2) patient related, (3) social and economic factors, (4) condition related, and (5) health-care system related.[1] These factors are often intertwined to varying degrees and influence a patient's ability to adhere to medications (Figure 13-1). These dimensions are to be considered as we assess medication adherence and choose strategies to improve adherence.

THERAPY-RELATED FACTORS

Medication Effects and Side Effects

All medications have potential side effects, and the number of side effects increases with the complexity of the regimen. Although clinicians may be vigilant for serious side effects, they may be less conscious of those that are not life threatening, but significantly interfere with a patient's functioning. Moreover, the patient may perceive the desired effect of the medication as an adverse side effect. For example, patients may take diuretic medications at night, leading to disrupted sleep due to frequent need to urinate. Instead, taking diuretics in the morning may relieve this problem. However, such changes in the

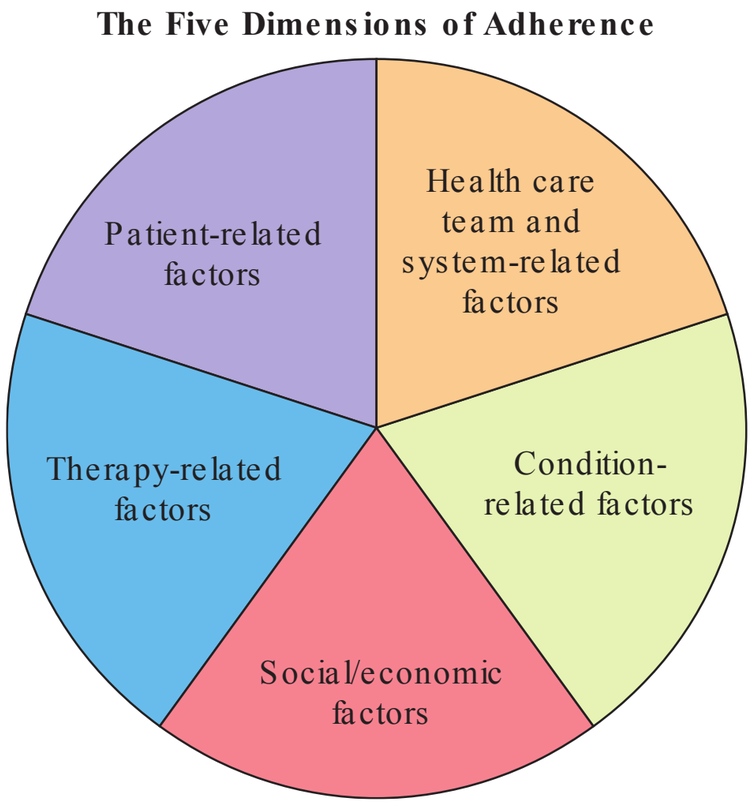


Figure 13-1. The five dimensions of adherence. Optimal treatment frequently requires addressing several barriers to adherence. Health professionals must follow a systematic process to assess all the potential barriers. (Adapted from Sabaté E. Adherence to Long-Term Therapies. Evidence for Action. Geneva: World Health Organization, 2003:27.)

dosing schedule may prove challenging for individuals who do not have ready access to bathroom facilities when they are away from their homes.

The seriousness of side effects is often idiosyncratic, and must be assessed for patients individually, as there will be different levels of tolerance for medication side effects. For example, although the cough associated with the use of angiotensin-converting enzyme (ACE) inhibitors is inconsequential for many patients, it may prompt avoidance in others. Patients may be reluctant to discuss certain side effects with their clinicians (e.g., loss of libido associated with some medications). Patients may not know what steps to take if they miss a dose of medication. They may not know when to take the dose of medication as soon as they remember, or to wait until the next regular dosing time. Medications used to treat depression require several weeks before any effect is seen and due to early side effects, patients may stop the medications because the side effects make them feel ill, and their depression is not yet getting any better. In addition to the actual effects and side effects of medications, unrelated new or recurrent symptoms may be attributed to a new medication by some patients and thus may contribute to poor adherence.

Regimen Complexity

The average older patient with two or more chronic illnesses is treated with more than six daily medications. Although many of these may be taken once daily, others may require multiple daily doses. Patients may experience scheduling conflicts associated with their medication regimens, particularly when their medication schedules change frequently, such as with warfarin, insulin, and diuretics. Some medications must be taken with food and others require an empty stomach. Patients with issues of food insecurity may not be able to adhere to the instructions of taking medications with food. This complexity is further compounded by the fact that certain medications must not be taken at the same time as others. Many work environments do not permit scheduled breaks to take medications or monitor effects of medications (e.g., blood sugar check for diabetes). Patients living in low-income housing units or who are homeless may not have access to proper storage facilities for their medications (e.g., refrigeration).

PATIENT-RELATED FACTORS

Confusion

Even if a patient chooses to follow recommendations, misunderstanding, uncertainty, and confusion about the actual recommendation can lead to poor adherence. Patients may recall and comprehend as little as 50% of what is conveyed to them in a medical visit,[10-13] and often do not have a clear understanding of the doses and indications for each of their medications. Additionally, patients may not appreciate that treatment of chronic conditions such as hypertension and diabetes require the ongoing use of medications, and consequently may fail to obtain refills once their prescription is completed.

Administration of medications to children is challenging because most medications come in liquid form. For example, a dose of medication may be ordered in milligrams; however, the parents and caregivers may need to be taught to convert the dose to milliliters or teaspoons for administration. The mathematical conversions often times can result in errors and confusion, leading to the administration of the incorrect dose of the medication. Care must be taken to ensure that parents and caregivers have clearly marked measuring tools and understand the conversions of doses. This also applies to adult patients who may require medications in liquid form.

Cognitive/Physical Impairments

Patients with cognitive impairments that result from aging or complications of underlying diseases (e.g., cerebrovascular disease) may be at particular risk for confusion with their medication regimens.[14] Patients require labeling instructions that they can understand. Large print may be required to accommodate those patients with visual impairment.

Language and Low Functional Health Literacy

Limited literacy is a worldwide problem and it is important that care be delivered at the level needed for patients. Language barriers and low functional health literacy[15] have been recognized as important contributors to confusion with medication regimens. Health literacy refers to patients' ability to "obtain, process, and understand the basic health information and services they need to make appropriate health decisions."[16] Patients who may be particularly vulnerable to low functional health literacy include older patients, those with lower levels of education and literacy, and those with limited English proficiency. As many as 50% of patients cared for at public hospitals and safety-net settings may have low functional health literacy.[17] The written word may not be sufficient for patients to get a clear understanding of medication administration instructions and providers will need to use pictures and drawings to promote medication adherence (see Chapter 15).[18]

Health Beliefs

Patients' beliefs about health, health care, or their particular medical conditions may differ substantially from those of their health-care providers. These beliefs may range from use of complementary and alternative medicines to religious beliefs and the conviction that there is no need to take medications if one is asymptomatic (often

encountered in the treatment of hypertension).[19] Such health beliefs on the part of patients do not invariably lead to poor adherence if the beliefs are acknowledged and integrated into the patient's overall treatment plan. Clinicians who engage patients in nonjudgmental discussions of their use of complementary and alternative medicines, for example, may be better able to establish the rapport necessary to enable improved adherence, as well as identify potential serious interactions among treatments.

SOCIAL AND ECONOMIC FACTORS

Social Support

Social support plays an important role in overall health and well-being, and appears to be instrumental in ensuring medication adherence.[20] Social support encompasses emotional (love, affirmation) as well as practical support (food, shelter, money, transportation). Patients who have a social network and environment that supports and promotes the behaviors that contribute to medication adherence may be more successful at following instructions of the providers.

Depression is common in the outpatient setting and particularly prevalent among those with multiple health problems.[21] Depressed patients are less likely to follow through on medical recommendations,[22] possibly because of hopelessness and lack of confidence in the effectiveness or worth of the treatment. Depressed patients also are likely to be isolated, lacking the social support necessary for adherence. The medication regimens for depression are frequently complex and often medication alone is insufficient for treatment.

Cost

The cost of medications is recognized as a common reason for medication poor adherence.[3,5,23,24] With the Affordable Care Act, more patients are eligible for insurance but still may not be able to afford it, or may have insurance that does not cover the cost of medications. Even those with prescription drug benefits are often charged high copayments for each medication, which may represent a significant portion of a low-income patient's monthly budget. Some health plans and systems will not pay for certain medications without a prior authorization, which requires patients to self-advocate, complete complex forms, and successfully negotiate alternatives with their clinician. Patients taking medications for chronic conditions may try to make their medications last longer (e.g., skipping doses, taking daily medications every other day), or fail to fill prescriptions when they are experiencing acute financial constraints.

Studies have shown that although clinicians understand that the cost of medications may affect adherence, they rarely initiate conversations about this barrier. Paradoxically, when they do, discussions frequently are not targeted to those patients most likely to have financial problems. Additionally, physicians often lack adequate knowledge of insurance and formulary restrictions to change their prescribing patterns, which could alleviate some cost burdens.[25-27]

Pharmacists are important resources for patients and other health-care providers to assist with medication costs. As an example, pharmacists can provide counseling for patients signing up for Medicare Part D to choose plans that cover their medications for low co-pay and prescription coverage plan fees.

CONDITION-RELATED FACTORS

Substance Use

Alcohol or illicit drug use is an important independent factor contributing to poor adherence, and may be more prevalent in patients challenged by depression or social isolation, which further affect adherence. Patients actively using illicit drugs or alcohol may be prone to erratic use or nonuse of prescribed medications. The use of illicit drugs or alcohol may worsen the conditions that their medications were prescribed to treat (e.g., hypertension, depression). The advent of effective pharmacologic-based treatments for addictions has led to efforts aimed at improving adherence among patients with dependence on illicit drugs or alcohol.[28]

HEALTH SYSTEM–RELATED FACTORS

> After leaving his job, Mr. Cruise lost his private health insurance. Mr. Cruise began receiving his care at the public hospital and because of formulary differences had to switch from one type of beta-blocker, which is taken once a day, to another type of beta-blocker, which is taken twice a day. Further, the medications that he takes at home have been changed during each of his four hospitalizations.

Navigating the health-care system can be overwhelming as patients try to determine where to obtain the services and resources needed to maintain their health. These systems can be an academic medical center, a community hospital, a government-run hospital, a neighborhood clinic, a pharmacy, a mobile clinic van, or a traditional healer's hut. The environment in which patients and clinicians discuss health-care recommendations can either support adherence or undermine it. The following are factors within the health-care system that may contribute to poor adherence.

Fragmented Care

Patients with multiple chronic illnesses often are treated by more than one clinician, each of whom may be prescribing

or adjusting medications. Recent technological advances have facilitated communication among physicians caring for the same patient (e.g., increasing use of electronic medical records), yet faulty or lapsed communication systems still contribute to confusion over care, as well as overt medical errors. These lapses are particularly likely to occur at the time of hospital discharge, when adjustments to the outpatient medication regimen are implemented, often without adequate patient education or communication with outpatient physicians. Community pharmacies are not connected with hospitals and the many community pharmacies in one city, for example, are not connected to one another to share patient information. Maintaining updated medication lists is a challenge. Using technology to bring these pieces of information together can result in more smooth transitions from the hospital to the pharmacy, to home, to the clinic, and back to the pharmacy. This communication needs to occur with all involved in the care of patient, such as the physician, nurse, pharmacist, social worker, dentist, patient, family members, and care givers.

Time Constraints

When arriving at their treatment recommendations, clinicians often do not have sufficient time to offer clear explanations or assess whether patients understand them. Unfortunately, very few health systems provide standardized education tools that clinicians can employ with patients who have been prescribed a new medication. Additionally, clinicians often feel that they do not have adequate time to explore differing health beliefs or any of the other patient factors that may contribute to poor adherence.

Pharmacists and pharmacy staff may feel pressured by similar time constraints limiting their potential to act as resources. In response to patients receiving inadequate medication counseling, the Omnibus Budget Reconciliation Act of 1990 (OBRA 1990) passed by Congress mandated that states improve their practices of educating patients about their medications. States responded in a variety of ways to provide the counseling and education to patients with 90% of states mandating that pharmacists provide face-to-face medication counseling for all patients receiving new prescriptions.[29] Another missed opportunity to discuss any medication-related problems and reinforce directions for taking the medications is when patients are picking up medication refills at the pharmacy.

Refill Restrictions

Many insurance plans impose restrictions on quantities of medications and the timing of medication refills. Such restrictions include limiting each prescription to a 30-day supply, allowing refills only when there are 2–3 days of medications left, and requiring physician approval for more than six total medications in a month. These restrictions can pose significant challenges for patients who need to fill prescriptions around complex work or family schedules, have difficulties navigating the bureaucratic processes, or have multiple chronic conditions whose medications may need to be filled on different days of the month.

Formulary Restrictions

Within a given class of medications, there are often multiple options with equivalent efficacy. Frequently payers reimburse for only one or two of the medications within a particular class, and require higher copayments or complete payments for other medications within the class. Clinicians usually treat a panel of patients with a variety of different insurance plans; therefore, they may be unaware of formulary restrictions and may fail to choose those with the lowest cost (and equivalent efficacy). Within a given plan, formularies often change (reflecting the availability of generic medications or negotiation of a lower price for a particular brand), requiring the patient to request another prescription from the clinician, or leading to confusion about pills of a different color or shape. Patients switch or lose jobs necessitating changes in, or loss of, their health insurance and subsequent formulary changes.

New medications within a given class, simply substituted in accordance with the formulary rules of the insurer, will likely appear different, and may be given on a different dosing schedule and may have a different side effect profile or interactions with other chronic medications. All of these can result in considerable confusion for patients.

THE HEALTH-CARE PROVIDER'S ROLE IN ASSESSING AND PROMOTING ADHERENCE

The clinician, within the context of the patient–clinician relationship, can play an important role in promoting adherence by (a) recognizing poor adherence; (b) identifying the factors that may be contributing to poor adherence; and (c) pursuing strategies that enhance the partnership with the patient (see Key Concepts).

PATIENT–CLINICIAN COMMUNICATION

Effective communication is critical to ensuring adherence, and is a hallmark of strong patient–clinician partnerships. Clear explanations of health recommendations minimize patient confusion. An environment that encourages bidirectional communication; establishes rapport; conveys compassion and respect; and normalizes nonadherence all make it more likely that factors impeding adherence

will be elicited. Such an environment increases patient satisfaction and trust in medical care, and contributes to a shared process of decision making about medical recommendations.

Patients who are poor, are members of race/ethnic minority groups, or have limited health literacy or English proficiency are often more likely to report less effective patient–clinician communication.[16] Increasing clinician awareness of the sociocultural context of their patients' health may improve patient–clinician communication, adherence, and overall health care.

Cultural competence education and training is essential for clinicians and staff to gain a wider perspective of the factors that interfere with effective communication. The use of interpreters is a must when a patient prefers to have their instructions given to them in their native language (other than English). Effective use of interpreters requires training (see Chapter 31).

IDENTIFYING PATIENTS WITH ADHERENCE DIFFICULTIES

> Mr. Cruise returns to his primary care physician after his last two hospitalizations. She expresses concern for his frequent admissions, and asks Mr. Cruise to speculate about the factors that might be leading to his worsening heart failure. She also states that sometimes it is difficult for patients to take a lot of medications every day, and wonders whether Mr. Cruise has ever experienced any difficulties taking his medications.

Adherence must be reassessed at regular intervals for all patients, particularly when new medications are started or existing medications are changed. Patients may be reluctant or embarrassed to admit that they are having difficulty with adherence. Patients may be unwilling to reveal their confusion, difficulty reading or understanding instructions, financial problems, or lack of the social supports necessary to maintain their regimens. They may feel that their health beliefs will not be understood or respected by their physicians. Some clinicians may make patients feel that their difficulty with adherence is unusual, further inhibiting discussion.

There are a number of ways to initiate discussions of adherence with outpatients (Table 13-1). These conversations should acknowledge that adherence can be difficult. Ideally such conversations use open-ended questions to engage patients and allow them to reveal the barriers that are most important to them, as well as more probing questions to discern the contribution of specific barriers.

Clearly, detailed comprehensive adherence assessment is a time-consuming process. However, many experts have suggested that for certain high-risk patients (e.g., the elderly, those with multiple chronic conditions, those with cognitive impairment or communication barriers, those on medications with a narrow therapeutic window), visits solely for the purpose of medication review are necessary. Such visits can be conducted by physicians, nurses, or clinical pharmacists,[30] who can focus on a review of the medications, their proper administration (e.g., metered dose inhalers, insulin), and potential side effects.

Table 13-1. Strategies for Assessing Adherence

- Use introductory statements that acknowledge the difficulty with adherence.
  "Taking pills every day can be hard. Most people have problems taking their pills at some point. I am going to ask you about problems you may have had taking your pills. I'm asking because I want to find a way to make it easier for you to take them. Can you tell me or show me how you take your medications?"
- **Confirm an understanding of the regimen.**
  Have patients bring in their pill bottles or make use of visual aids. If patients are confused, use strategies for increasing recall and comprehension of regimen.
- **Ask about their medication schedule over the past 3 days, one day at a time.**
  Start with the day prior to the visit and go through the entire day, asking how medications were taken or about missed doses. Then proceed with the day 2 days before the visit. If no doses were missed in the preceding 3 days, ask about the last time a dose was missed. Again make use of visual aids or pill bottles.
- **Ask about reasons for missed doses.**
  Begin with open-ended questions and then prompt if unable to elicit a response, suggesting common reasons why adherence may be difficult—forgot, too busy with other things, too many side effects, feeling sick or depressed, ran out of pills, difficulty paying for medications, etc.
- **Ask about effects that are particular to the medication regimen.**
  Again, prompts may be necessary—nausea, headaches, depression, sexual side effects, difficulty swallowing pills, lack of access to refrigeration, difficulty obtaining pills from pharmacy.

Source: Machtinger E, Bangsberg DR. Adherence to HIV antiretroviral therapy. Accessed September 27, 2005. Available at http://hivinsite.ucsf.edu/InSite.jsp/InSite?page=kb-03-02-09.

IDENTIFYING FACTORS CONTRIBUTING TO POOR ADHERENCE

> Mr. Cruise states, "the doctors in the hospital keep changing my meds around." He admits to being confused about what medications he is supposed to be taking. Mr. Cruise acknowledges sometimes missing doses of medications, especially at the end of the month when "money is tight." His physician asks, "When you go to pick up your medications from the pharmacy do you ask to speak to the pharmacist or does the pharmacist ask you to describe any issues you have with taking your medications?" Mr. Cruise replies, "No, I have not." Finally, Mr. Cruise expresses increasing hopelessness at the loss of his job and his worsening medical condition. "I just didn't think my life would turn out this way."

Assessing medication adherence requires a dialogue involving not only what the patient is doing, but how they are doing it. Other issues can be elicited from the patient by asking, "What gets in the way of you taking your medications regularly?" There often are health issues, psychosocial issues, environmental issues, behavioral issues, and other competing demands of life that gets in the way.

Adherence first requires that patients have a clear understanding of their health-care providers' recommendations. Clinicians directly contribute to poor adherence when explanations of instructions are not clear and there is no assessment of whether the patient understands the recommendations. Comprehension can be increased by using techniques that ask patients to restate information to assure that it was understood,[14,31,32] such as with the "teach-back method" (Figure 13-2). This interactive communication loop is useful for gauging the extent to which recommendations are understood by patients and for initiating a dialogue between clinicians and patients about other specific challenges to adherence. The "teach-back" method may help uncover cognitive impairments or literacy limitations and prompt the clinician to refocus educational efforts to accommodate these challenges. This dialogue may uncover differing patient perceptions or health beliefs about their medications and serve as an entry point for further exploration of these beliefs.

Clinicians must explore factors unique to particular patients or to the environment in which the clinician practices. Awareness should include accurate and up-to-date knowledge regarding medication side effects, costs, prescriptions from other clinicians, and restrictions to formularies.

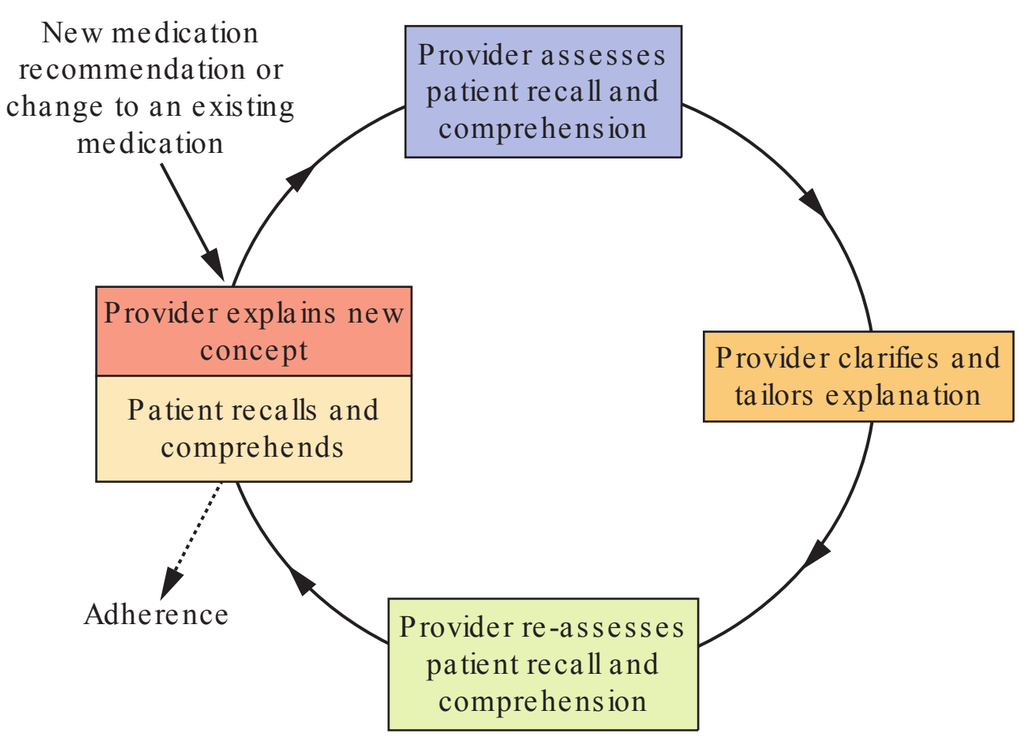


Figure 13-2. Interactive communication loop for educating patients regarding a change in their medication regimen. (Adapted from Schillinger D, et al. Closing the loop: Physician communication with diabetic patients who have low health literacy. Arch Intern Med 2003;163(1):83-90.)

- Recognize that poor adherence to medications is common.
- Engage in effective patient–clinician communication to assess and promote medication adherence among all patients.
- Accurately identify patients who have difficulty with medication adherence.
- Identify the patient, clinician, and systems factors that may pose barriers to medication adherence.
- Target specific interventions that are appropriate to particular medication adherence barriers.

INTERVENTIONS TO PROMOTE MEDICATION ADHERENCE

> Mr. Cruise and his physician review his medication regimen together. She asks him to return the following week to meet with the clinic pharmacist in order to reinforce his understanding of his current regimen, and asks that he bring all of his pill bottles so that outdated medications and those no longer indicated can be properly discarded. She arranges for Mr. Cruise to see a social worker to review services he might qualify for to alleviate his financial crisis. Finally, she discusses Mr. Cruise's depressive symptoms with him, including options for treatment.

Interventions to promote adherence must be customized to the patient's needs. Multiple strategies may be needed to assist patients to take their medications correctly. Identifying the barriers that impede the success of patients and matching them up with an intervention is essential to overcoming the barriers. A "one-size-fits-all" approach is not appropriate; strategies to promote adherence should be tailored to the specific needs of the patient.

Several interventions have been studied that have the potential to promote adherence. These interventions, in concert with a clinician's recommendations, may help enhance adherence if targeted appropriately.

SIMPLIFIED TREATMENT REGIMENS

Single daily dosing of medications, reduced numbers of medications, and coordination of doses should be used, as appropriate. A regular review of medications can identify ones that are not working or not needed. This strategy has been shown to be consistently effective in a variety of chronic conditions.[33,34]

COLLABORATIVE PLANNING

Patients and clinicians should collaborate to develop dosing schedules that accommodate the patient's daily schedule. Side effects should be discussed whenever new therapies are initiated. Follow-up visits should address side effects and dosing schedules; plans should be designed as these conditions change. Collaborative planning also may include discussion of financial barriers to the initiation of medications and may include referrals to social workers or in-home support services to facilitate adherence.

Pharmacists are the most accessible health-care provider in the community, and patients should be encouraged to partner with their community pharmacist to ensure that the management of the medication regimens is correct and to assess if the patient is experiencing any side effects. The pharmacist serves as a resource to answer medication-related questions and address concerns.

PATIENT EDUCATION

Patients should be educated about their disease and the ways in which adherence to their medication regimens can alter the course of their disease. Educational interventions of this type are particularly important for chronic illnesses that require ongoing medications. Clinicians providing the education should assess and ask the patient by what methods they learn best. It may be a combination of print and pictorial materials, or other media to reinforce key concepts. Pharmacists, physicians, nurses, dentists, and health educators may all effectively describe disease processes (for chronic diseases such as diabetes, asthma, HIV) or the proper use of difficult-to-administer medications (e.g., insulin, metered dose inhalers). Education efforts should be readdressed at regular intervals as repetition helps solidify the patient's comprehension of important concepts and instructions.

MEDICATION REVIEW VISITS

Patients may benefit from a visit devoted exclusively to a review of their medications. Pharmacists are particularly well suited to conduct such visits, as they are able to focus exclusively on medications, their proper administration, and potential side effects. It has been shown that the inclusion of pharmacists on a multidisciplinary care team increases adherence and reduces adverse events.[35,36]

Review of medications is important not only at the initiation of a new medication regimen, but also for patients whose medications may not have changed substantially. Such reviews should address whether treatment for a particular condition is still indicated and consistent with the latest evidence, as well as whether a regimen can be simplified.

CASE MANAGEMENT

For many patients, the complexity of their disease (e.g., heart failure, HIV), their comorbid illnesses (e.g., psychiatric illness, substance use), or their social situation (e.g., homelessness) may pose additional challenges to adherence that can be most effectively addressed with intensive, multidisciplinary interventions. In these interventions, clinicians may partner with nurses, social workers, health educators, pharmacists, dieticians, community health educators, and others to provide follow-up to support and identify ongoing barriers to adherence.[37,38]

SYSTEM REMINDERS

Integrated health systems and large-chain pharmacies have employed automated reminder systems to enhance adherence with chronic medications. Patients may receive reminders to refill their medications several days prior to finishing their current prescription and may be reminded again if they fail to fill prescriptions in a timely manner.[39] Some systems identify patients who persistently under fill their prescriptions for a particular chronic disease and may use this information to target referrals for case management or other more intensive interventions.[40]

Some disease management programs incorporate regular automated telephone contact with patients to screen for a variety of potential difficulties with disease management, including medication adherence. These systems permit timely identification of adherence difficulties as well as targeted use of nurse, health educator, pharmacists, and physician time to focus on particular patients with adherence difficulties.[41]

DIRECTLY OBSERVED THERAPY

In this approach, patients receive their medications each day from a health provider (or reliable surrogate) and are observed taking them. It has been used successfully to address poor adherence in the treatment of tuberculosis,[42] and has been suggested for treatment of HIV and substance use.[43,44]

MEDICATION ADHERENCE DEVICES

The following devices are particularly useful for patients who are confused or have complicated medication regimens.

Medication Organizers

Pillboxes, medi-sets, and other versions of medication organizers are readily available in clinics and pharmacies.

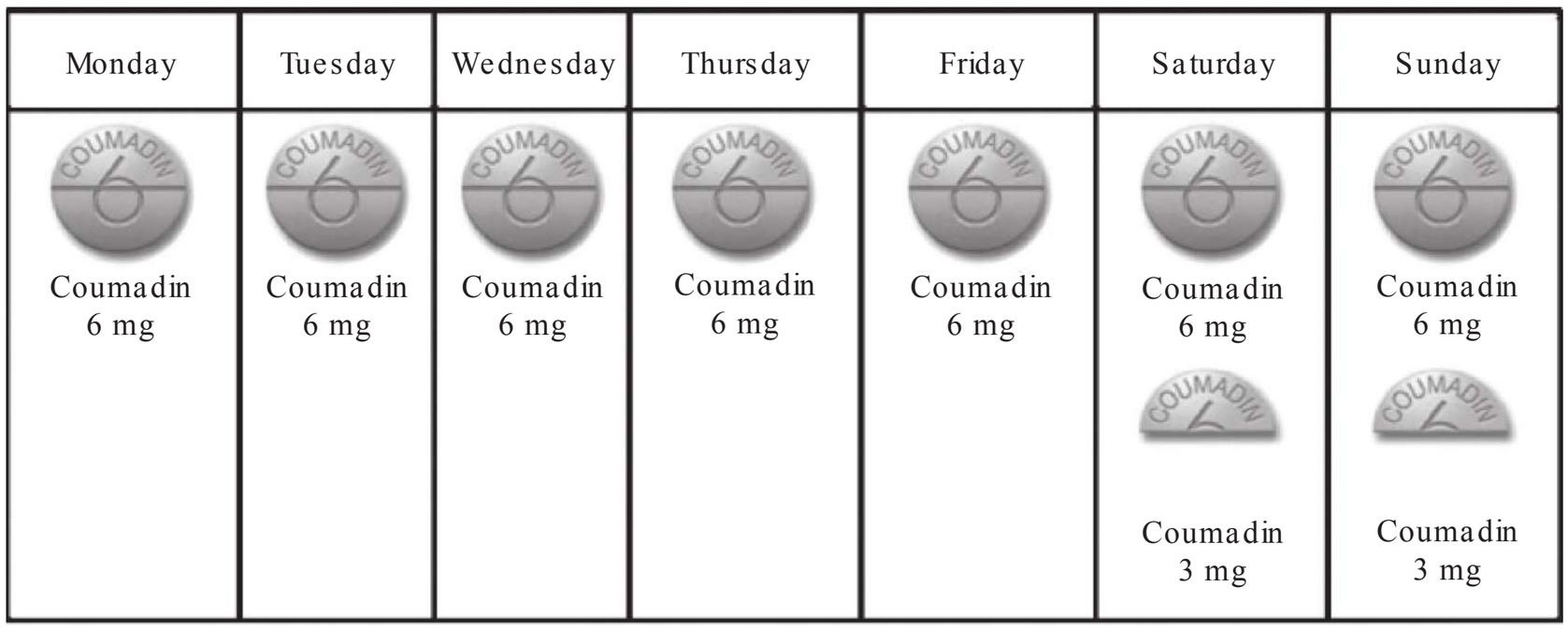


Figure 13-3. Visual medical schedule for warfarin therapy. (Adapted from Machtinger EL, Wang F, Chen LL, Rodriguez M, Wu S, Schillinger D. A visual medication schedule to improve anticoagulation control: a randomized, controlled trial. Jt Comm J Qual Patient Saf. 2007;33:625-635.)

Pharmacists, case managers, or nurses can help facilitate filling the organizer correctly. Pharmacies may pre-fill pillboxes or bubble packs that may further enhance use of these devices.

Visual Medication Schedules

Visual medication schedules are tools in which pictures of the prescribed medications are placed on a weekly calendar in the corresponding doses. One such visual medication schedule designed, developed, and piloted by Edward Machtinger and Dean Schillinger and produced by Tim Peters and Company, a health product software company, is displayed in Figure 13-3. Such schedules are now available through some computer programs and from drug manufacturers. Many clinicians create these schedules by simply affixing the actual pill to a paper calendar.

Reminders

Reminder devices such as alarms on watches or beepers can enhance adherence. Medication reminder applications for smart phones can be another option for patients. This is particularly true of regimens that require frequent daily dosing and regimens in which doses must be taken on a tightly timed schedule. This strategy has been used effectively in the treatment of HIV.[45]

NONCLINICIAN FACTORS

It is important to note that a number of the interventions described in the preceding sections would be most effective were they to be implemented systematically, but have not been for a variety of reasons, and are often out of control of the individual clinician. As such, advocacy efforts also should occur outside of clinicians' offices for substantive reform to occur. Reduction in pill burden by combining preparations into a single pill (e.g., HIV) could greatly simplify the regimens of patients with chronic diseases. Innovative packaging (e.g., oral contraceptives) and labeling of pharmaceutical products could enhance understanding for patients with linguistic or literacy barriers, and widespread use of assertive technology by pharmacy systems could enhance refill adherence.

CONCLUSION

Vulnerable patient populations are at risk for poor medication adherence. It is crucial to engage these patients as partners in the maintenance of their health. Patients can help identify contributing factors to their poor adherence and facilitate the development of targeted interventions to promote adherence. Clinicians who work alone trying to solve the problem of poor medication adherence are not as effective as those who use a team approach that includes the patient, nurses, and pharmacists all working together.

There is no "one" solution that will work for all patients and individual patients may require multiple strategies. Accurately identifying the specific factor(s) contributing to nonadherence for a specific patient can allow for targeted intervention. Effective communication strategies, strong patient–clinician relationships, use of available resources aimed at improving patients' understanding of medications, and health system improvements can together facilitate and promote medication adherence.

DISCUSSION QUESTIONS

1. What factors identified in this chapter most commonly pose challenges for medication adherence in your patients?
2. How might you initiate a discussion about medication adherence with a patient? How might follow-up discussions assess and promote medication adherence?
3. What additional interventions are you aware of for promoting medication adherence and how have they been used?

Assessing And Promoting Medication Adherence

- Establish an effective patient–provider partnership.
- Recognize that medication adherence is a major challenge for patients and they need to be supported.
- Recognize that there are other factors beyond those related to the patient that contribute to poor medication adherence.
- Employ interactive communication techniques to assess recall and comprehension about medications to minimize confusion and elicit patient concerns.
- Identify the various patient, clinician, and system factors that may make medication adherence a challenge and develop communication strategies to identify these.
- Tailor-specific interventions designed to improve medication adherence to the needs of your patient.

RESOURCES

Educate before You Medicate. National Council on Patient Information and Education. http://www.talkaboutrx.org

Medline Plus. Drug Information Service of the US National Library of Medicine (NIH). http://www.nlm.nih.gov/medlineplus/druginformation.html

Safe Medication. Drug Information site of the American Society of Health-Systems Pharmacists. http://www.safemedication.com

Rx Assist. Patient Assistance Program Center. Programs run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. http://www.rxassist.org

A Program Guide for Public Health: Partnering with Pharmacists in the Prevention and Control of Chronic Diseases http://www.cdc.gov/dhdsp/programs/nhdsp_program/docs/Pharmacist_Guide.pdf

Summary of Barriers to Adherence and Potential Solutions

Barrier	Potential Intervention
Side effects	Simplify treatment regimens Patient–clinician discussion of effects and potential side effects within context of daily activities Medication review (inquire about common side effects, over-the-counter medication use, herbal supplements)
Complexity	Simplify treatment regimens Collaborative planning Ongoing patient education to reinforce key concepts (particularly for chronic diseases such as asthma, diabetes, heart failure, HIV) Medication review visits Case management (multidisciplinary teams that may be particularly effective for chronic diseases such as heart failure, diabetes, HIV) Adherence devices • Medication organizers • Visual medication schedule: may be particularly useful for regimens with changing daily doses (e.g., warfarin) • Reminder devices: particularly if doses must be taken on strict time schedule • System refill reminder
Confusion	Simplify treatment regimen Collaborative planning Medication review visits; encourage patients to bring pill bottles, have the patients describe how they take the medications, correct any errors, and clarify instructions Adherence devices • Medication organizers: consider prefilled pill boxes • Visual medication schedule: may be useful even for regimens that do not change daily • System refill reminders
Health beliefs	Collaborative planning to explore health beliefs and possible integration of medication regimen into these beliefs (readdress at subsequent visits as well)
Social support	Collaborative planning: include family members and care givers in education about disease and proper medication use Case management may be particularly useful in patients lacking adequate social supports
Depression and substance use	Treat underlying depression and/or substance use Case management programs that target individuals with psychiatric or substance use problems
Cost	Simplify treatment regimen: be aware of formulary restrictions and financial consequences of the introduction of a new medication

	Collaborative planning: address financial barriers to medication use directly; elicit help from social worker, for questions about insurance and social services
	Medication review: consider discussion of essential versus nonessential medications, and the consequence of restricting different classes of medications
Fragmented care	Enhance communication among clinicians, particularly during hospitalizations
	Medication review visits: encourage patients to bring pill bottles and review medications changed or initiated by other clinicians
Time constraints	Multidisciplinary health-care team • Collaborative planning: identify financial problems and elicit assistance of social workers, in-home support, etc. • Medication review visits: pharmacists • Additional patient education: nurses, pharmacists, health educators • Case management: integrated approach that may be appropriate for particular disease management or high-risk populations
Refill restrictions	Be aware of refill restrictions when choosing medications
	Collaborative planning: explicit discussion of how to fill medications
	System refill reminders
Formulary	Be aware of formulary restriction when choosing medications

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Chapter 14

Navigating Cross-Cultural Communication

JudyAnn Bigby, MD and Alicia Fernandez, MD

Objectives

- Define cross-cultural communication.
- Review evidence for the need to improve cross-cultural communication.
- Describe challenges to effective cross-cultural communication and how they have an impact on clinical care.
- Describe strategies for effective cross-cultural communication.

Ms. Jones is a 56-year-old African-American classroom assistant who was hospitalized with a stroke. Her course rapidly deteriorated and her physicians determined that aggressive treatment would be futile. They approached her family with the recommendation that life support be removed. The doctors explained that Ms. Jones had multiorgan failure and little hope of recovery. Her family, a daughter and two sisters, were shocked by this recommendation and accused the physicians, all of whom were white, of substandard care.

INTRODUCTION

When patients and physicians interact, cross-cultural communication is a common occurrence as patients and clinicians differ in many important ways. Patients from vulnerable populations (including persons from racial and ethnic minority populations, immigrants, low-income persons, and persons with low educational attainment) and health-care providers face unique challenges to effective communication. These challenges are borne of the differences in life experiences, cultural norms, assumptions, expectations, and barriers inherent in a health-care system in which the biomedical model of health predominates. While this chapter takes an example of an African-American family interacting within the US health-care system, cross-cultural communication is observed in every country, and, to a certain extent, in every clinical encounter. Patients and physicians may share a common background and have similar expectations of the clinical encounter, yet still differ radically in their level of knowledge or in their personal values. Navigating cross-cultural communication is the norm in most medical encounters.

Culture is a coherent system of beliefs, values, and lifestyles held by individuals, their communities, and the larger sociopolitical structure in which they live. Culture is a dynamic entity and is responsive to changes such as socioeconomic position, immigration, and other factors (Figure 14-1).

Cross-cultural communication in the context of health care is both complicated and complex because of these multiple determinants of culture and the inherent complexities of medical care. Effective cross-cultural communication acknowledges the interplay of multiple factors, including race, ethnicity, cultural norms, religion, socioeconomic position, and education to achieve a common understanding or aim. Effective cross-cultural clinical communication also results in sharing of key information and demonstration of caring. This chapter discusses common barriers to effective cross-cultural communication

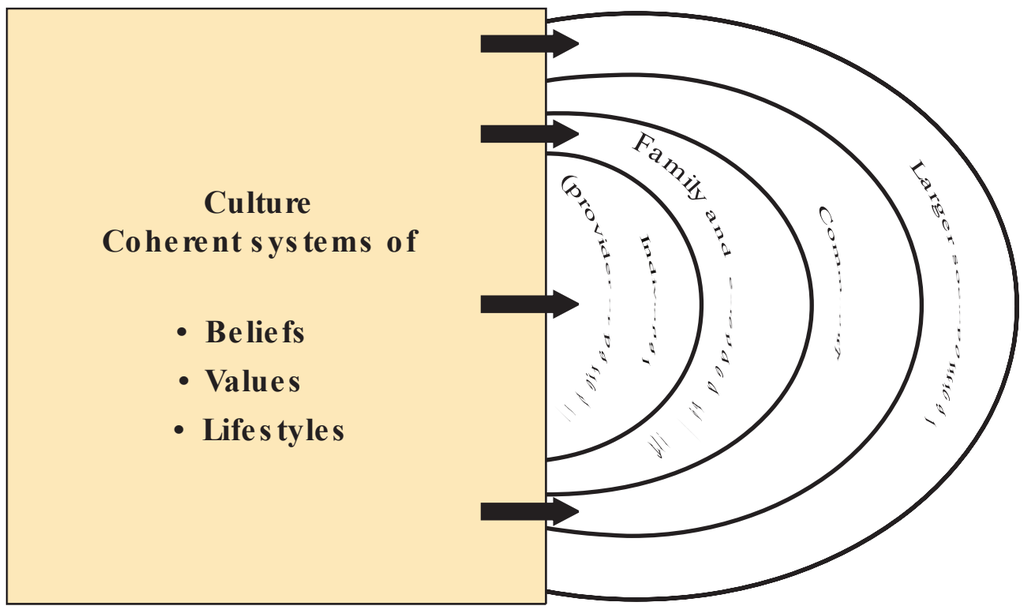


Figure 14-1. Culture is a coherent system of beliefs, values, and lifestyles. Individuals' culture is influenced not only by their personal circumstances but also of their families and extended families' cultures, the culture of their communities, and the culture of the larger social political environment. Individuals, families, communities, and societal cultural systems are dynamic and responsive to multiple forces such as socioeconomic conditions.

and how to overcome them. (For a discussion of the effective use of interpreters, see Chapter 31).

EXTENT OF THE PROBLEM

There is abundant evidence that patients are concerned about the lack of effective communication with their physicians and other health-care providers. Patients perceive communication problems with their physicians regardless of background—including English-speaking, white, educated patients. That said, communication problems are more common for minority patients and for patients with limited English proficiency. The Commonwealth Fund reported results of a national survey in which 39% of Latinos, 27% of Asian Americans, 23% of African Americans, and 16% of whites reported problems with communication, specifically that their doctor did not listen to everything they had to say, they were not able to understand their doctors, and they were not able to ask questions during their visits.[1] Similar reports of poor doctor–patient communication exist in surveys of patients across many different countries with very different health-care systems.[2,3]

Physicians give more information and offer more support and encouragement to patients who ask questions and express concerns. Creating an obvious feedback loop, patients ask more questions when physicians engage in partnership-building behaviors, but physicians engage in more partnership-building behaviors when the patient is more educated.[3-5] Latinos and Asian Americans commonly report that physicians do not adequately involve them in decision making.[6,7] African Americans are also less likely than whites to report that their doctors include them in decision making, especially when the patient and doctor are of different races.[8] Physicians tend to be more verbally dominant and engage in less patient-centered communication with African-American patients than with white patients, less likely to explain test results, medical conditions, and treatments.[9]

Ineffective cross-cultural communication is of particular concern in the management of chronic diseases, in high stakes decision making in acute care, and in the context of end-of-life care. African Americans report that they would like to discuss preferences for resuscitation in the event of a cardiopulmonary arrest, but they are more likely than whites not to have done so.[10] African Americans are more likely to want family members to make decisions for them at the end of life compared with others, but believe that physicians would not involve families in collaborative decision making.[11,12]

Despite the recent attention to cultural competence in medical school curricula, several studies document persistent deficits in cross-cultural communication among medical students and physicians.[13]

CHALLENGES IN CROSS-CULTURAL COMMUNICATION

> Ms. Jones' family does not care that the medical evidence suggests that further treatment is futile. Their life experience has taught them that life is precious, withstanding suffering is a sign of faith, and that African Americans have often beaten the odds and defied death. They do not completely trust the health-care system to do the best for Ms. Jones.

Multiple barriers at the patient, provider, and health system levels contribute to the communication difficulties in this scenario. Clear disagreement has arisen between Ms. Jones' family and her medical team about appropriate care. Interactions between the family and the health-care providers are strained. The health-care providers do not understand the family's reaction; they believe the family does not understand the limits of medical technology in this clinical situation. The family believes the physicians are acting out of prejudice or bias and are not offering Ms. Jones the same care she would receive were she white or young. The physicians did not involve the family in their decision making, but simply presented them with their recommendation about withdrawing life support. They have failed to consider potential differences that may have led to this communication breakdown, including racial discordance between the treatment team and the Jones family, religion, spirituality, and the relevant broader social context.

PATIENT-LEVEL BARRIERS

Acceptance of Inadequate Communication

In some cultures, it is considered inappropriate for patients to ask questions of the health-care provider.[14]

In dominant US culture, patients with lower socioeconomic status or low health literacy are often intimidated in the clinical interaction and do not solicit additional information or express their wishes.[3] Researchers have demonstrated that patients can learn assertiveness skills that result in more participatory clinical interactions.[15]

The Ask Me Three campaign (http://www.npsf.org/?page=askme3) is an example of a large-scale patient education campaign aimed at activating patients to ask more questions. Health coaches, who meet with the patient before the clinical interaction, can be very helpful in empowering patients to ask questions and express their own values. For issues as diverse as pain control in cancer patients in the United States[16] to reproductive care in poor Indonesian women,[17] coaches or navigators can play a key role in improving patient–doctor communication.

Trust

Lack of trust of the health-care provider may be a significant barrier to effective communication. One strategy that some patients may use to protect against stereotyping by clinicians is to withhold information that they perceive would be viewed negatively. Trust is particularly relevant for groups that have historically experienced bias in the health-care system, as reflected in denial of service, segregated service, or blatantly inferior service.[18] The legacy of past abuses such as the US Public Health Service Syphilis Experiment continues to influence some African Americans' ability to trust the system.[19] In 2010, revelation about a related Guatemala syphilis experiment has caused widespread distress among Latinos.[20]

Health Literacy

Health-care clinicians often overestimate patient understanding of key concepts in care, including prevention, self-management, and chronic disease processes. This can result in significant discordance in visit goals and expectations. It is important for providers to develop skills that permit them to ascertain the extent of patients' understanding of their clinical condition, and to work with them to establish appropriate, mutually acceptable goals and strategies for addressing clinical concerns (see Chapter 15).

CLINICIAN-LEVEL BARRIERS

Lack of Cultural Competence

Clinician deficiencies are the most frequently described contributors to poor cross-cultural communication, likely because they have been the most thoroughly researched. Physicians are less satisfied with their interactions with patients who are racially, ethnically, and linguistically diverse. They perceive that patients from these groups are less interested in prevention, managing their illnesses, and engaging in healthy behaviors.[21,22]

Frustration may stem from the clinicians' lack of awareness regarding the influence of their own cultural norms. Clinicians are often unaware that they reveal negative attitudes to patients, particularly when addressing the health beliefs and behaviors of unfamiliar cultures. Physicians and patients often do not discuss the "cultural rules" that underlie their interactions until there is a problem. Perhaps, most importantly, physician attitudes and lack of communication skills can lead to decreased patient trust.[23]

Stereotyping

Stereotyping is a particularly important challenge when caring for vulnerable patients. Clinicians often wish to learn about the specific health beliefs of distinct cultural groups, which can be quite helpful. However, knowledge about general cultural beliefs in specific populations is insufficient for effective cross-cultural communication. Persons from racial and ethnic minority groups represent a wide range of cultures, beliefs, and attitudes depending on place of birth, educational attainment, socioeconomic position, acculturation, and other factors. So, knowledge of general health beliefs and attitudes of a group of people can be used only to generate hypotheses that can be tested with individual patients.

The unconscious (and certainly the conscious) use of appearance or some other personal characteristic to stereotype patients is a routine occurrence. The 2003 Institute of Medicine report, Unequal Treatment, documented a long list of studies documenting bias in diverse clinical fields from cardiac care to HIV/AIDS diagnosis and treatment, and the treatment of pain.[24] In another example of stereotyping, studies have shown African Americans were judged more likely to be substance abusers and were rated as less intelligent and less educated when compared to whites.[25]

INTERSECTION OF PATIENT AND CLINICIAN BARRIERS

Patients and clinicians each enter interactions with assumptions about the other party, and cultural factors influence their predetermined expectations about how the encounter will proceed (Figure 14-2).[17] Clinicians need to be conscious of how these assumptions are developed and then negotiate expectations and goals based on input from the individual patient (Box 14-1).

SYSTEMS-LEVEL BARRIERS

Historically, health-care professionals have received little or no training in cross-cultural communication. In addition, many system-level forces obstruct improvements in effective communication (Box 14-2). Furthermore, the

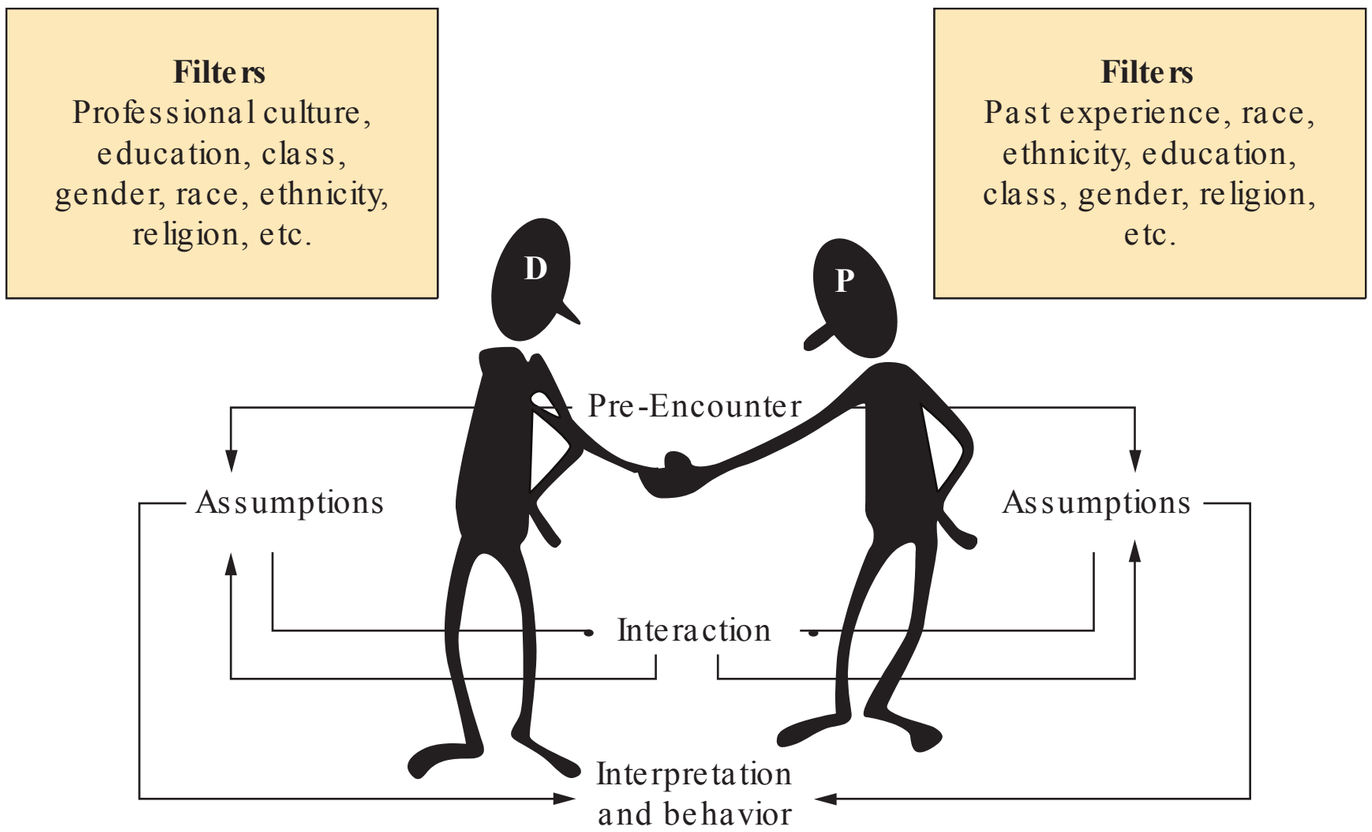


Figure 14-2. Both the doctor (D) and patient (P) use filters that influence assumptions made about each other and each understanding of the interaction. These assumptions influence the interpretation of what happened in the interaction and subsequent behavior. When the doctor and/or patient are aware of how they use their filters, they may reexamine their assumptions and thus influence the interaction and interpretation of the interaction.

physical limitations of clinical sites often do not facilitate the unique decision-making styles of some groups. In cultures in which family decision making is valued above individual one-on-one interactions, examination rooms may be too small, yet conference rooms to hold family meetings are frequently nonexistent, and the hours of operation often do not accommodate work and caretaking schedules of extended families.

Box 14-1. Common Pitfalls

- Failing to appreciate cultural differences, rendering one's own values dominant, and dismissing the value systems held by others
- Making the medical model the only or dominant paradigm
- Stereotyping groups as a shortcut to understanding whether and how the individual patient values cultural norms
- Bias and lack of personal awareness of bias
- Using medical jargon and technical language that impede communication
- Failing to check for meaning and understanding with the patient
- Failing to inquire about patient preferences for decision making
- Failing to express empathy in cross-cultural communication clinical encounters
- Failing to express empathy in communication mediated via an interpreter
- Lack of awareness of historical events that may shape patient illness and beliefs

SOLUTIONS TO EFFECTIVE CROSS-CULTURAL COMMUNICATION

> Ms. Jones' family asks permission to include their pastor in the next discussion about her care. They want reassurance from the clinical team that she will be treated with dignity and that her needs will not be ignored. They also want to make sure that a family member who is arriving from out of town has an opportunity to see her before she dies. The clinicians are able to accommodate this request.

Effective cross-cultural communication requires the health-care clinician to integrate awareness of her own cultural beliefs and attitudes with her clinical expertise,

Box 14-2. Systems-Level Challenges to Effective Cross-Cultural Communication

- Growing diversity of the US population without concurrent diversification of health-care professional staffs
- Increasing emphasis on technology and use of electronic medical records, which may undermine and underemphasize the need to talk to patients face to face
- Pressure on health-care clinicians to care for more and sicker patients in shorter clinical encounters
- The "inverse care law" whereby the sickest and most vulnerable patients often have access to the least amount of care
- Reimbursement systems that reward procedural interventions and care of healthy patients over care for complex patients or socially vulnerable people

Table 14-1. Respect Model

Action	Comment
Respect	Show a demonstrable attitude involving both verbal and nonverbal communications.
Explanatory model	What is the patient's point of view about his or her illness? How does it compare to the provider's point of view? Both points of view should be elicited and reconciled.
Sociocultural context	How do class, race, ethnicity, gender, education, sexual orientation, immigrant status, and family and gender roles impact care?
Power	Acknowledge the power differential between patients and physicians.
Empathy	Put into words the significance of the patient's concerns so that the patient feels understood.
Concerns and fears	Elicit the patient's emotions and underlying concerns.
Therapeutic alliance/trust	Provide a measurable outcome that enhances adherence and engagement in health care.

Source: Model developed by the Boston University Residency Program in Internal Medicine Diversity Curriculum Taskforce and adapted from Bigby J. Beyond culture. Strategies for caring for patients from diverse racial, ethnic, and cultural groups. In Bigby J, ed. Cross-Cultural Medicine. Philadelphia, PA: American College of Physicians, 2003.

Table 14-2. Assessing Personal Self-Awareness

1. How do you define your own racial or ethnic identity?
2. What did you learn to value while you were growing up?
3. Which features of your own racial or ethnic group do you view positively?
4. Which features of your own racial or ethnic group do you view negatively?
5. What are some characteristics that are important to your identity?
6. While you were growing up, were the schools and neighborhoods homogenous, or racially and/or ethnically mixed? What about socioeconomically? At what point in your life did you have the opportunity to interact with people who were different from you?
7. Are there culturally distinct groups with which you feel comfortable?
8. Are there culturally distinct groups with which you feel uncomfortable?
9. What is the racial/ethnic or sociocultural characteristic of the patients with whom you feel most competent in establishing rapport and a treatment plan?
10. What is the racial/ethnic or sociocultural characteristic of patients with whom you have the most difficulty establishing rapport and establishing a treatment plan?
11. How do factors related to your racial or ethnic identity and/or from your life experience affect how you interact with patients from backgrounds that are different from your own?

Source: Adapted from Goldman R, Monroe AD, Dube C. Cultural self-awareness: a component of culturally responsive patient care. Ann Behav Sci Med Educ 1996;3:37-46.

and use knowledge of the patient's individual values and cultural and social context, to accomplish mutually determined goals of care. Table 14-1 shows a model developed by the Boston University Residency Program in Internal Medicine Diversity Curriculum Taskforce for caring for patients from diverse racial, ethnic, and cultural groups.[26]

PERSONAL AWARENESS

For the clinician, exploring personal identity is an important first step in developing effective cross-cultural communication. Understanding how personal race, ethnicity, culture, socioeconomic position, and other characteristics influence one's practice as a physician can be enormously helpful (Figure 14-1).

Assessing personal awareness is an ongoing process of self-reflection throughout a career. Individual clinicians may become more aware of the assumptions they make about patients through critical reflection on their own background and clinical practice. A set of questions designed to assess and enhance personal awareness is shown in Table 14-2.

INDIVIDUALIZED CULTURAL ASSESSMENT

"You've got to find out the identity of a person to even get to know them."

(Patient, as quoted in Kagawa-Singer)[8]

Discovering a patient's identity is enormously rewarding, and is the first step toward effective cross-cultural communication. Prior to the clinical encounter, clinicians may collect general information about specific cultural groups with whom they are unfamiliar, recognizing that they risk unhelpful stereotyping by applying these to individual patients without confirmation.

General cultural information should be considered a foundation for understanding cultural norms. This information can be used to generate hypotheses about the potential health beliefs of a particular patient. These hypotheses then can be directly tested with an individual patient or family. For example, persons of Chinese origin commonly do not want to be directly informed about grave diagnoses. To test whether a particular patient's beliefs are congruent with this hypothesis, a clinician might say, "In general, I give patients as much information as possible about their medical conditions. How do you feel about me sharing more detail with you now, or would you prefer that I speak with someone in your family, or all of us together? All patients are different, and I want to make sure I do what you prefer." This approach, often termed "cultural humility" rather than cultural competence, is more patient centered.[27,28]

Using a narrative, open-ended style, as opposed to asking specific questions, may be effective. With the cultural context in place, the specifics of a patient's life experience

Box 14-3. Basic Information in the Cultural Assessment

- Level of formal education
- Racial or ethnic self-identification
- Generational status (e.g., first-generation immigrant)
- Level of encapsulation within ethnic and family social network (e.g., living in a community with a large concentration of a cultural group)
- Immigration history (if applicable)
  - Degree of migration back and forth to country or region of origin (if applicable)
  - Area of origin in native country
  - Occupation currently (and before migration, if applicable)
- Sexuality and important sexual and nonsexual relationships
- Religion and spirituality
- Personal or family experience in the health-care system or with relevant illness
- Decision-making preferences: who, when, how
- Information preference: how much and how delivered

gain greater meaning (Box 14-3). Finally, this approach is most useful when combined with an awareness of important historical events that may be germane to the patient's life history. Knowing that Cambodia endured one of the world's worst genocides during the late 1970s is as important as knowing common Cambodian attitudes toward Western medications.

CREATE AN ENVIRONMENT THAT BUILDS TRUST

Building trust is a key component of effective cross-cultural communication. Patients view trust-building behaviors as a sign that clinicians are invested in them as individuals and that they want to help patients, and articulate behaviors that they would like physicians to exhibit (Table 14-3). Trust-building behaviors display respect and build rapport. Small actions such as asking a patient how she prefers to be addressed go a long way to demonstrate respect. Clinicians often forget the power differential that exists in their relationships with patients. Demonstrations of empathy are meaningful ways to improve communication with patients. Empathic behavior requires active listening (nodding, encouraging), picking up and restating on patients' concerns ("Sounds like you found that…"), identifying the factual content of the patient's statement (What I heard you say…"), asking about and affirming affective responses ("I hear how frightening that was for you"), and requesting clarification of unclear statements.[29]

Empathic statements have been shown to increase trust. A recent study found that patients preferred

Table 14-3. Trust-Building Behaviors

Actions	Attitudes
Introduce yourself by name, title, and role. Ask the patient what she or he prefers to be called. Make an effort to make the person comfortable. Do not appear to be rushed. Ask personal questions. (How is your daughter doing now? Is school any better for her?) Use plain language. Listen for the patient's style of telling about symptoms. Listen to questions. Be responsive.	Do not make assumptions. Pay attention to cultural beliefs. Acknowledge and respect different perspectives. Distinguish the person as an individual. Display genuine concern.
Hold patient information as confidential. Ask patient if they are satisfied with the appointment. Apologize when there is a problem.	

physicians who portrayed difficult facts within an optimistic context.[30] While not always possible, this too may help create trust: "let's hope for the best, while we work on the rest." Eliciting the patient's concerns is always an effective partnership-building tool. Finally, a responsive, culturally competent health system can help support the clinician–patient relationship. For example, the use of navigators or health coaches has also been shown to increase patients' trust in their primary care providers.[31] The end result of these behaviors should be a meaningful therapeutic alliance.

Some aspects of a patient's cultural values and beliefs are relevant to clinical situations and some are not. Let the patient provide advice and guidance. For example, ask about interactional norms (how younger clinicians show respect for elders; how older clinicians allow young patients to ask questions or express an opinion; how gender roles translate to clinical situations). Assess an individual patient's values and beliefs, and incorporate this information into clinical assessments and decision making. Identify strategies taken from the patient's cultural orientation that can be used to enhance the therapeutic alliance; acknowledge those that seem counterproductive. These behaviors are consistent with behaviors and attitudes that others have described as being important for improving cross-cultural communication and that exhibit patient-centered approaches.[27,32] It is important to remember that, as illustrated in Figure 14-2, the absence of these clinician behaviors may be interpreted as disrespectful and biased, based on the patient's past experience of racial, ethnic, or cultural biases.

IDENTIFY PATIENT'S EXPLANATORY MODEL OF ILLNESS

"The patient needs to open up to tell you these things."
(Patient as quoted in Kagawa-Singer)[10]

Identifying patient's explanatory model of his or her illness is a fundamental aspect of cross-cultural communication. Kleinman and colleagues[33] have developed an anthropologic approach to eliciting a comprehensive understanding (Box 14-4). When asked in a respectful, caring manner, these questions can facilitate an understanding of the patient's expectations and provide important information that a traditional medical interview would miss. Preface these questions with a respectful introduction, such as "I know that patients and doctors sometimes have different ideas about what causes certain symptoms or illnesses. I'd like to know more about your ideas about your problem."

Acknowledge what the patient has shared by summarizing what you have heard. Describe to the patient your assessment of the problem and acknowledge any discrepancies between your interpretation and the patient's. Avoid medical jargon or technical language. Explain how your assessment addresses the concerns identified by the patient. Check to see if the patient has heard and understood what you said. "What questions do you have about what I have just said? What should I explain in more detail?"

It may be useful to summarize the understanding of the patient's major concerns. From this process, the patient and clinician can develop a problem list that reflects their negotiation. If the patient is hesitant to agree, explore the source of hesitation and begin to negotiate again.

NEGOTIATE A PLAN FOR FURTHER EVALUATION AND TREATMENT

Once the problem list and possible diagnosis are identified, the clinician can begin to make recommendations for next steps. Ask the patient whom he would like to involve in the process and then accommodate the patient's request by agreeing to meet with important family members or others. Address patient confidentiality up front and ask for clear guidance about how much information should be shared with the family.

The process of developing a diagnostic and treatment plan affords an opportunity to ask about the patient's use of alternative and complementary therapies and about the patient's expectations for treatment. As the clinician outlines possible strategies for further diagnostic evaluation or appropriate treatments, the clinician should allow the patient to stop and ask questions. Confirm the patient's comprehension by asking him or her to describe his or her understanding of the next steps. Provide language and literacy-level–appropriate written instructions for patients who identify the problem, tests, and relevant instructions for undergoing the tests, and any prescribed medications. The information also should outline any self-management instructions for the patient. Ask the patient how well he thinks he can adhere to the plan. Note possible financial barriers, explaining that some tests or medication may be expensive and that the clinician is willing to seek alternatives.

Patients often wait until the end of the encounter to raise concerns and fears. Budget time accordingly, and use empathic statements to build rapport.[29] Sometimes, patients rely on nonverbal cues to convey these concerns. They also may use indirect questions to inquire about issues about which they are uncomfortable. They may pose hypothetical situations or talk about what happened to a family member or friend. Clinicians may answer indirectly or if they feel it is appropriate, ask the patient about how the hypothetical applies to her.

Box 14-4. Anthropologic Approach to Eliciting a Comprehensive Understanding

- What do you call your problem?
- What name do you give it?
- Why do you think your illness started?
- When did it begin?
- How severe is it?
- What do you fear most about your illness?
- What are the major problems your illness has caused?
- Do you have any ideas about what treatment you should receive or others who would be helpful?

From Kleinman A, Eisenberg L, Good B. Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. Ann Intern Med 1978;88:251-258.

NEGOTIATING THROUGH DISAGREEMENT

When there is a disagreement between the clinician and patient, it is important to acknowledge it. Identify the patient's most pressing concern and begin to outline what can be done to address it. If the patient rejects the clinician's concerns or diagnosis, the clinician should return to the principles of cultural humility and ask clarifying questions to identify core areas of agreement and disagreement.

IDENTIFY DESIRED OUTCOMES

Effective cross-cultural communication can improve clinical outcomes from both the patient and clinician perspective.[34,35] Effective communication is associated with increased satisfaction for the patient and clinician.[6] Patient adherence and an enhanced understanding of the

disease process and treatment also may improve with effective cross-cultural communication.[36,37]

CONCLUSION

Cross-cultural communication is a critical skill for today's medical clinicians, irrespective of where they practice. Effective communication in the context of significant cultural differences requires concerted efforts to ensure open exchange. Fortunately, the skills required for effective communication are attainable by most health-care clinicians.

Navigating Cross-Cultural Communication

- Assess your own cultural beliefs and attitudes.
  - —Acknowledge your major cultural identity.
  - —Identify possible areas of discomfort.
  - —Identify possible areas of bias.
  - —Examine your assumptions when dealing with individual patients.
- Perform a cultural assessment on the patient.
  - —Identify the patient's major cultural identity by asking the patient.
  - —Ask the patient about decision-making and information-sharing preferences
  - —Assess level of formal education, employment history, immigration history, role of religion and spirituality, and past experience in the health-care system.
  - —Test hypotheses about health beliefs and attitudes using general information about specific cultural groups but do not apply to patients without individual confirmation.
- Create an environment that builds trust.
  - —Employ trust-building behaviors in interactions with all patients.
  - —Identify the patient's explanatory model of illness and the patient's desired outcomes.
  - —Negotiate a diagnostic and treatment plan that incorporates the patient's model.
  - —Acknowledge the patient's concerns with empathy.
  - —Identify patient preferences for family or other key individuals' involvement.
  - —Use empathic statements with all patients
  - —Encourage the patient to ask questions.
  - —Summarize concerns and check for accuracy.
- Recognize that effective communication requires ongoing relationship building and continuous reassessment.
- Recognize that all communication between clinicians and patients shares key elements of cross-cultural communication.

Negotiating Conflicts

Patients and clinicians do not always agree on a plan of action, even when the clinician has tried to be sensitive to the cultural perspective of the patient. When the patient and clinician disagree about the course of action in a clinical situation, it is important for them to recognize that there are effective strategies for resolving the conflict. The conflict rarely should lead to patients seeking care elsewhere, although sometimes that is the solution to the problem.

Define the problem.

Make sure the clinician and patient agree on the conflict.

Clinician: "Mr. Smith I think that we have come to a point where we don't agree on the next course of action. I understand that you want to be admitted to the hospital, but I believe your problem does not require hospitalization. I think that with appropriate antibiotics your infection will resolve and we can provide close follow-up for you as an outpatient."

Mr. Smith: "Dr. Jones, I know my body and I don't feel well. The last time a doctor sent me home when I thought I should be admitted I had a heart attack at home."

Examine your own motivations.

Have any other factors influenced your decisions?

Does the patient have unique social or other circumstances that warrant consideration? If you are not sure, ask.

Acknowledge the patient's concerns. "It must be frightening that I am suggesting sending you home."

Demonstrate trust-building behavior. (Make an effort to make the patient comfortable. Do not appear to be rushed.)

Be responsive to the patient's statement. ("I heard you say you have been sent home inappropriately before.")

Demonstrate empathy. ("That must have been scary for you. I am sorry that you had to go through that experience.")

Ask questions to identify the patient's specific concerns. ("Sometimes, some people have not been treated fairly in our health care system. Do you think that is a problem in your case?" or "What do you think will happen to you if you go home today?")

Be responsive to patients' concerns. ("I understand your feelings that you were mistreated in the past.")

Identify opportunities for a compromise.

Ask whether the patient thinks there are alternatives.

Ask if he or she has other family members or someone else with whom he or she is close and who should be involved in the discussion.

Devise a list of possible compromises between the two positions.

Ask if patient is comfortable with one of the alternative plans.

Restate the compromise you have reached and ask if patient has same understanding.

Assess the patient's satisfaction with the outcome.

Acknowledge the patient's willingness to share his or her thoughts.

Apologize about the disagreement.

Ask if he or she is satisfied with the resolution.

Ask what can be done to avoid conflicts in the future.

DISCUSSION QUESTIONS

1. Discuss some of the barriers to effective cross-cultural communication at the patient, clinician, and health systems level. What are some strategies for addressing systems level barriers?
2. Think back to a time when you needed health care. What was your experience like? Did you have a good relationship with your clinician? What made the relationship work? How was it problematic? What role did your education level or race or ethnicity play?
3. How would you design a program to train clinicians in clinician-effective cross-cultural communication?
4. What other elements of a social history are important to obtain? How do these add to the basic cultural information data?
5. Return to the case of Ms. Jones. Write a role play that illustrates how you think her clinicians could approach her family with news of Ms. Jones' poor prognosis. How would the clinicians inquire about end-of-life care for Ms. Jones?

RESOURCES

http://www.diversityrx.org. Provides a summary of the wide spectrum of strategies available to overcome linguistic and cultural barriers to care, and describes their application in model programs around the country.

http://www.ethnomed.org. The EthnoMed site contains information about cultural beliefs, medical issues, and other related issues pertinent to the health care of recent immigrants to Seattle or the United States, many of whom are refugees fleeing war-torn parts of the world.

http://nccc.georgetown.edu/. The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.

http://www2.massgeneral.org/disparitiessolutions/index.html. The Disparities Solution Center groups research, resources, and tools to address health-care disparities at multiple levels.

http://xculture.org/resources/general-resource-guides/cultural-competence-resources/. The Cross Cultural Medicine Program provides resources and training to bridge health-care providers and institutions and diverse communities to advance access and quality of health care.

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Chapter 15

Improving the Communication Exchange: A Focus on Limited Health Literacy

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Objectives

- Define health literacy.
- Identify patient and system level factors that contribute to the challenges faced by patients with limited health literacy.
- Review best practices in clear communication.
- Discuss how to facilitate question asking.
- Illustrate how to confirm comprehension and identify topics for further focused review.
- Describe characteristics of health literate health-care organizations.

INTRODUCTION

Mrs. S, a 65-year-old woman with type 2 diabetes, high blood pressure, chronic obstructive lung disease (COPD), and lumbar back pain, comes to her primary care clinic for routine follow-up. Mrs. S takes metformin, glipizide, benazepril, Advair®, Spiriva®, albuterol, and ibuprofen. She lives alone as her husband passed away. She manages her own medications, shopping, cooking, and cleaning. She has a daughter who visits her weekly. During her appointment, she reports difficulty picking up all of her medications due to "insurance issues." She has not been regularly checking her blood sugar at home and reports "cheating" a lot lately, especially when baking for her grandchildren. She complains of worsening back pain, limiting her ability to attend her weekly dance class. She missed her scheduled mammogram because she got lost looking for the mammography center at an offsite location. Her recent hemoglobin A_{1c} has increased from 7.5% to 9.0% and her diabetic foot exam shows decreased sensation. She leaves her visit with an appointment with the medical social worker to discuss medication insurance coverage, a handout on lower back stretches to practice at home, a referral to prosthetics to pick up diabetic shoes, instructions on daily foot care, a blood sugar tracking form with instructions to monitor her blood sugar three times a day to help decide if she should be started on insulin, a map of the hospital's off-site facilities to help her find the mammography center, and a computer-generated summary of her primary care visit. She is given the phone number to reschedule her mammogram, and follow-up appointments to see the diabetes nurse in 6 weeks and her primary care provider in 3 months.

In order to maintain good health, patients are expected to communicate concerns clearly with providers, understand written and verbal instructions, partner with providers to make decisions about screening and choose treatment options, engage in self-management activities at home and in their communities, and negotiate a complicated and often fragmented health-care system. These are complex tasks requiring a high-level of health literacy. The various definitions of health literacy (Box 15-1) reflect a dynamic interplay between the literacy demands and attributes of the health-care environment and the personal skills of patients.

This chapter outlines the difficulties faced by patients with limited health literacy, with a focus on patient and

Box 15-1. Defining Health Literacy

Institute of Medicine: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

The Patient Protection and Affordable Care Act of 2010, Title V: "The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions."

World Health Organizations: "The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health."

system level factors. The chapter highlights the central role that clear communication plays in promoting health equity and high-quality care. We also provide clinicians with a set of strategies to improve understanding for patients with limited health literacy. These considerations are relevant not only to clinicians but also to anyone on the health-care team who interacts with patients or plays a role in designing or implementing health education or programming.

DEFINITIONS AND THE SCOPE OF THE PROBLEM

Health literacy skills are broader than general literacy skills. In addition to basic reading skills, the relevant skills needed by a patient include document-reading skills; writing skills; interpersonal communication skills; the ability to use numbers for computation, measurement, and risk assessment; and the skills needed to navigate systems—online, on the phone, and in physical space. Limited health literacy results when the complexity of health tasks and the demands of the health-care system exceed the skills of patients. Health literacy is content and context dependent. Limited health literacy is common and is more likely in people over the age of 65 years, individuals with chronic diseases, minority population groups, immigrants, and those without a high school education.[1,2] Acute illness or anxiety over a new diagnosis can also affect patients' health literacy. As providers increasingly depend on patient skills and knowledge to manage chronic diseases such as diabetes, congestive heart failure (CHF), and COPD, ensuring that the literacy demand of the health-care system matches the literacy skills of individual patients which is of utmost importance. Because all patients, regardless of health literacy level, benefit from clear, direct communication

Box 15-2. Common Pitfalls in the Care of Patients with Limited Health Literacy

- Overestimating patients' health literacy level
- Using jargon
- Discouraging question asking with body language or words
- Sharing too much information and focusing on non–action-oriented information
- Relying on words alone
- Choosing written materials that are too complex or at too high of a literacy level

and other literacy-friendly communication techniques, experts recommend "universal precautions," or applying clear communication strategies, discussed later, in all clinical encounters (Box 15-2).

IMPACT ON HEALTH OUTCOMES

Limited health literacy has been linked to a wide range of adverse health outcomes.[3] Compared with individuals with adequate health literacy, individuals with limited health literacy have higher rates of chronic illness, greater difficulty with medication management and poorer rates of medication adherence,[4,5] less knowledge about their chronic diseases,[6] higher rates of hospitalizations due to chronic medical conditions such as CHF and diabetes,[7-10] have more emergency room visits and hospitalizations,[11,12] and experience worse chronic disease outcomes.[13] Recent research among older adults connects health literacy level with cognitive decline, such as decreases in executive functioning.[14]

Limited health literacy has an impact on patients' interactions with their providers. Patients with limited health literacy have a more difficult time understanding explanations about medical conditions and instructions about medication changes.[15] Owing to embarrassment or shame related to incomplete understanding, patients with limited health literacy are often more passive during encounters, asking fewer questions, despite having greater need for reinforcement.[16] These gaps in understanding make self-management and follow-up activities more difficult, and may contribute to poorer health outcomes. In addition, gaps in understanding can impede shared decision making and informed consent.[17]

Limited health literacy may affect patients' ability to access care and navigate the complexities of the health-care system. For example, insurance companies or government programs often introduce hurdles that may be insurmountable to people with limited health literacy. Consequently, people may not seek care or may present for health care late with more advanced disease.

While most of these outcomes studies have focused on English-speaking countries, studies from other countries replicate these findings.[13] In addition, newer studies are beginning to analyze health literacy skills beyond reading, such as numeracy and listening skills, and explore these skills' impacts on health outcomes.[18,19]

SCREENING FOR LIMITED HEALTH LITERACY

Miscommunication and misunderstanding are common during health-related interactions. Nonetheless, providers do a poor job of predicting who will have a difficult time understanding. Providers also tend to overestimate patients' health literacy level.[20,21] A number of instruments to assess health literacy have been developed and studied, primarily for use in the research setting. The two most commonly used research tools, the Rapid Estimate of Adult's Literacy (REALM) and the Test of Functional Health Literacy (TOFHLA), are word recognition and document utilization tests, respectively. While both tools have abbreviated forms, these shortened versions are cumbersome and can be intimidating to use in the clinical setting. A newer screening tool, the Newest Vital Sign, asks patients to interpret information contained on nutrition labels, mimicking real-life health management behaviors.[22] In addition, a single-item self-reported screening question, "How confident are you in filling out medical forms?" can be useful in identifying patients with limited health literacy.[23,24] However, each of these screening tools focus primarily on reading and document interpretation skills, and to a lesser extent numeracy, as a proxy for health literacy skills overall. These tools omit assessment of interpersonal, bidirectional, communication skills—speaking or explaining and listening or verbal comprehension—literacy skills central to successful health-related exchanges.[25] Despite the availability of these screening tools, most health literacy experts and national health policy organizations recommend against routine screening for limited health literacy.[15] There is insufficient evidence that screening improves health outcomes or enhances patient–provider relationships.[26]

SYSTEM LEVEL FACTORS THAT CONTRIBUTE TO HEALTH LITERACY CHALLENGES

There is growing appreciation that characteristics of the health-care system contribute to, or can ameliorate, the challenges experienced by individuals with limited health literacy skills.[27,28] Training health-care professionals to communicate clearly and to choose literacy-friendly, written reinforcement tools are important steps to promote health equity for individuals with limited health literacy, but these strategies are often insufficient. As we saw in Mrs. S's case, patients experience health literacy-related challenges not only within the clinic setting and while performing self-management tasks at home, but also as they negotiate health insurance plans, navigate health-care facilities, and communicate with other members of the health-care system team. Health-care organizations can recognize and address the system level factors that increase literacy demands. An Institute of Medicine (IOM)-commissioned paper[29] describes 10 attributes of "health literate organizations" (Box 15-3), providing guideposts for organizational change to achieve an environment that promotes access and understanding for all patients, regardless of health literacy level.

Box 15-3. Attributes of a Health Literate Organization[29]

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement programs.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audio/visual materials, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communication about medicine.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

STRATEGIES TO IMPROVE UNDERSTANDING FOR PATIENTS WITH LIMITED HEALTH LITERACY

> Mrs. S comes into clinic for follow-up after a recent admission to the hospital for cellulitis. During her hospital stay, she is started on insulin. She has been staying with her daughter since leaving the hospital 5 days ago. Since discharge, she has been feeling lightheaded and intermittently shaky. She reports that she has not been checking her blood sugar at home because neither she nor or her daughter know how to

use the new glucometer. When asked to explain how she is taking her medications, she pulls out six pill bottles, three inhalers, and insulin. "I am taking medications too many times a day! I take my diabetes pills at breakfast and dinner because the label says take twice a day, but this new one for my leg says take every 12 hours, so I am taking it at breakfast and trying to remember to take it at 8 PM, but I forget most days." A closer look at her medications show a pill bottle of benazepril 20 mg and a pill bottle of Lotensin®20 mg. When asked if she is taking both, explaining that both pills are the same medication, she responds "I take all my pills, those two have different names, are different shapes, and different colors!" Her fingerstick glucose is 70 mg/dL 2 hours after breakfast, and her blood pressure is 95/60 mm Hg.

Mrs. S's hospital discharge story highlights how the challenges faced by patients with limited health literacy are directly connected to the complexity of health-related tasks. In order to appropriately and safely manage her health after a hospitalization, Mrs. S is expected to learn a number of new concepts and activities: how to measure and inject insulin, how to recognize the warning signs of hyperglycemia and hypoglycemia, how to use a new glucometer, and how to manage a complex and changing medication schedule. These concepts are challenging for all patients to understand and integrate even under the best of circumstances, particularly when patients are acutely ill. In addition, Mrs. S's daughter is enrolled as a new caretaker, learning unfamiliar ideas and tasks to help her mother. She is suffering from concerning medication side effects, hypotension and hypoglycemia, due to inadequate preparation for self-management. The remainder of this chapter describes how clear communication strategies can help bridge the literacy gap and support patients to understand and appropriately act on health information, regardless of literacy level.

COMMUNICATE CLEARLY AND SIMPLY WITH ALL PATIENTS

Since it is difficult to tell who will have a difficult time understanding, clinicians should not make any assumptions about who has limited health literacy. Instead, they should apply "universal precautions," and aim to communicate clearly and simply with all patients.

First, clinicians should use simple, nonmedical words ("living room language"), when speaking with patients. Health-care professionals tend to forget that part of their training focuses on learning a new specialized language and set of concepts that take years of schooling to master. Providers often use jargon—specialized medical words—such as colonoscopy, radiologist, audiology, contraception, benign, that are often meaningless to patients. If a provider must use a medical term, she should take care to provide translation into plain, everyday language, using metaphors relevant to patients' lives. However, even "translating" jargon into simple terms may not help with understanding.[30] The best strategy is to simply avoid jargon and acronyms altogether, whenever possible. In addition, "value" words, such as "regular" exercise, "balanced" diet, "heavy" lifting, "stable" dose, may mean something very different to patients. Instead, clinicians should provide clear and concrete instructions. The aforementioned examples can be adjusted to the following: "Try to walk for 20 minutes three times a week. And do not lift more than 10 pounds at a time until your surgeon says it is OK to lift more."

In addition, mathematics and numeric concepts are challenging for many patients. Whenever possible, clinicians should do the math for patients, minimizing computational burden. In addition, providers can present statistical information in absolute risk (10 out of 100 people), using frequencies instead of percentages, and should consider using visual aids, such as icon arrays or bar graphs. When speaking about risk over time, clinicians should choose time frames relevant to patients' lives, such as a 10-year interval.[31]

EMPLOY CLEAR, CONCISE COMMUNICATION AND AVOID INFORMATION OVERLOAD

Large amounts of information presented by providers can easily overwhelm patients. For example, at the start of this chapter, Mrs. S's primary care provider introduced a variety of concepts and tasked her with numerous activities to do at home, inundating her with new information and activities. Instead, during patient interactions, clinicians should select a discrete set of skills or action items on which to focus, limiting each visit to no more than two or three key ideas. Rather than focusing clinical discussions solely on teaching facts about diagnosis, providers should highlight skills and action items that patients need to know to care for their health.

It is also important for clinicians to be specific when giving instructions, especially about medications. If a provider tells a patient, "take two pills twice a day," how is the patient supposed to know what time of day to do that? If a provider gives a patient a suppository without further instruction, how will the patient know that the medication should not be swallowed? If a provider instructs a parent to "give your child two teaspoons of medication every 4 hours," will the parent know what a teaspoon is without further clarification? In Mrs. S's case, she did not realize that the instructions on her medication bottles stating "take twice a day" and "take every 12 hours" meant the same thing, adding unneeded complexity to her medication schedule and causing her to miss doses of her antibiotic. Simplifying medication schedules; adopting a universal medication schedule, a schedule that gives instructions

using explicit time intervals, for example, morning, noon, and evening instead of three times a day; and communicating clearly about how and when medications should be taken can assist patients in improving adherence.[32,33] In addition, differences in generic versus trade name medications and changes in pill appearance confuse patients as well as providers. Given our current system, with unpredictable changes in covered medications and differences between pharmacies and manufacturers, there is little to be done to avoid confusion at all times. Providers must be aware of these challenges and aim for as much clarity and consistency in prescribing as possible. As such, medication reconciliation is a particularly critical component of each encounter for all patients, but especially those with limited health literacy.

ESTABLISH A COLLABORATIVE LEARNING ENVIRONMENT

Establishing a collaborative learning environment in which patients are not embarrassed to ask questions can improve open communication exchange. Important steps to establishing this environment are listening actively and reflectively, without interrupting, and assessing patient understanding and eliciting beliefs prior to giving explanations, so that discussions can emerge from a common ground. Individuals with limited health literacy are less likely to ask questions to their providers, despite having greater need for explanation.[34] Providers can facilitate and encourage question asking through their body language and the words that they use. Providers who ask, "Do you have any questions?" as they stand up to leave the examination room, will not engender authentic requests for clarification. When clinicians ask patients if they have any questions, patients must believe the clinician has both the time to listen and willingness to answer. Further, providers can normalize questions by asking "What questions do you have?" with body language that suggests that they are open and available to explain things further. Making eye contact and mirroring patients' language can also help. Clinicians can consider using question-generating tools such as the Ask Me 3 campaign or Questions are the Answer Campaign and encourage patients to write down questions prior to their appointments or while waiting for their providers.[35,36]

CONFIRM UNDERSTANDING

After sharing new information, clinicians should ensure understanding by using the "teach-back" or "show-me" approach. With this technique, clinicians ask patients to explain back, in their own words, any instructions or new information, to ensure that the provider explained things well. When introducing new tasks, such as learning to use a new glucometer, as in Mrs. S's case, providers should have patients demonstrate the activity step by step. These methods are not intended to test patients; rather, they are an opportunity to identify gaps in understanding and highlight topics that require further explanation (see Core Competency).[37,38] The teach-back and show-me method have been shown to improve patient understanding and have been highlighted as a best practice by safety experts.[39,40] Confirming comprehension complements strategies to enhance question asking are an opportunity to ensure that all concepts are clear, even when patients say they have no questions.

USE COMMUNICATION AIDS

In addition to speaking clearly and understandably, and creating a positive learning climate, it is often useful to employ multiple channels for communication. Reinforcement through several teaching modalities can improve comprehension and retention.[41] Enlisting help from family members and educating them as well can also support a patient's self-management skills. In Mrs. S's case, the loss of her husband, who may have provided key assistance, likely contributed to her deterioration. Teaching her daughter could also help reinforce Mrs. S's skills. Although not a cure-all for all misunderstandings, literacy-appropriate written handouts, diagrams, videos, interactive media, and telephone interventions can help reinforce, clarify, and remind patients of important health information.

Health systems should select printed patient education material that is culturally and linguistically appropriate and adheres to clear communication and low-literacy guidelines. These guidelines include use of plain language, use of the active voice, focus on action items, and adherence to a fourth- to sixth-grade reading level. Unfortunately, most available health materials are still above the recommended sixth-grade reading level.[42] Online resources are available to guide those who develop novel materials.[43] Health educators should solicit input from limited literacy populations when developing or choosing new materials whenever possible. There is also promising evidence that automated telephone support, videos, and interactive computer programs can assist with chronic disease management, end-of-life discussions, and medication education.[44-48] Medication adherence aids, such as pill boxes, medi-sets, diagrammed pill charts, and improved warning labels can help patients take medications correctly and reduce medicine-related errors.[49,50] In addition, as health-care delivery evolves to a model of team-based care, health system planners should consider the role that all members of the health-care team can play in reinforcing health messages, both during clinic sessions and as follow-up between clinic visits.

CONSIDER STRUCTURAL AND INSTITUTIONAL FACTORS THAT HINDER OR ENHANCE UNDERSTANDING

In addition to improving communication within the clinical encounter, providers and health-care professionals can serve as health literacy champions, advocating for the system level changes needed to transform their organizations into a "health literate health-care organization" (see Box 15-3).[51] This includes advocating for improved navigability of health-care facilities, ensuring that appropriate health educational materials are available and emphasizing the central role of health literacy in organizational planning and quality improvement initiatives. It is important that all members of the health-care team, from the front desk clerk to utilization management staff, be trained in health literacy best practices.

CONCLUSION

Patients' ability to understand health information and skillfully navigate the health-care system is at the foundation of high quality, equitable health care. Limited health literacy is one of the numerous communication challenges faced by patients. Physical disabilities, such as hearing and visual impairment, and cognitive decline also impact patients' ability to comprehend and act on health information. In addition, limited English proficiency (see Chapter 31) and cultural beliefs about health and the health-care system play a central role in communication dynamics, and these barriers often interact and with limited health literacy to further impede communication.[52] Nonetheless, it is imperative that health-care professionals take responsibility for improving understanding by communicating clearly with all patients, prioritizing information and limiting information overload, creating a safe learning climate, confirming understanding using the teach-back method, and employing communication aids. In addition, health-care professionals can advocate for adaptations at the system level that will lower the literacy demands placed on patients, becoming health literacy champions within their team, their clinic, or their health system.

Steps Providers Can Take To Improve Communication

- Use plain, everyday words during discussions.
- Limit your learning objectives to no more than three per encounter.
- Be specific in your recommendations and instructions.
- Assess patient understanding and elicit beliefs prior to launching into explanations.
- Use the teach-back technique to confirm understanding about concepts and self-management tasks.
- Use multiple communication channels to reinforce understanding.
- Focus on a brief set of action items.
- Create a culture of question asking and authentic dialogue.
- Teach all members of the care team and health-care organization best practices in clear communication.

Planning for Safe Hospital Discharge by Closing the Loop

Mr. J, a healthy 45-year-old man who smokes cigarettes, is admitted overnight for a deep venous thrombosis that developed after driving 12 hours to visit his family in Oregon. The plan is to discharge him home on anticoagulants for 3 months. He will be sent home with a week of enoxaparin injections to take with his warfarin until his anticoagulation is appropriate on the warfarin.

The team's intern, nurse, and pharmacist are to teach Mr. J how to inject enoxaparin, and new concepts related to anticoagulants, including risks signs of bleeding, the meaning of new medical terminology such as INR, and interactions with foods and medications.

The nurse reviews the steps Mr. J needs to take to inject his enoxaparin:

Mr. J walks through the steps with the nurse observing, but he leaves out the step of cleaning the skin with an alcohol swab before the injection. The nurse again reviews the steps and has Mr. J walk through the steps again. This time, Mr. J gets all of the steps right. Finally, Mr. J administers his morning dose, ensuring that his technique is correct (see Figure 15-1).

The intern caring for Mr. J also "closes the loop," ensuring that Mr. J knows concerning complications of his blood thinner treatment, by employing the teach-back method. Mr. J is able to correctly state signs of bleeding, but forgot that he should hold his warfarin and come to the clinic for a blood test. The intern makes that clarification, and upon a second teach-back loop, Mr. J is able to state all items correctly. The intern closes by asking what questions Mr. J has. Mr. J is unclear on when to stop injecting himself with enoxaparin and where to go to get his blood checked. The intern clarifies these things and gives Mr. J written instructions in simple, clear language.

For a video demonstrating the teach-back method, see https://www.youtube.com/watch?v=IKxjmpD7vfY

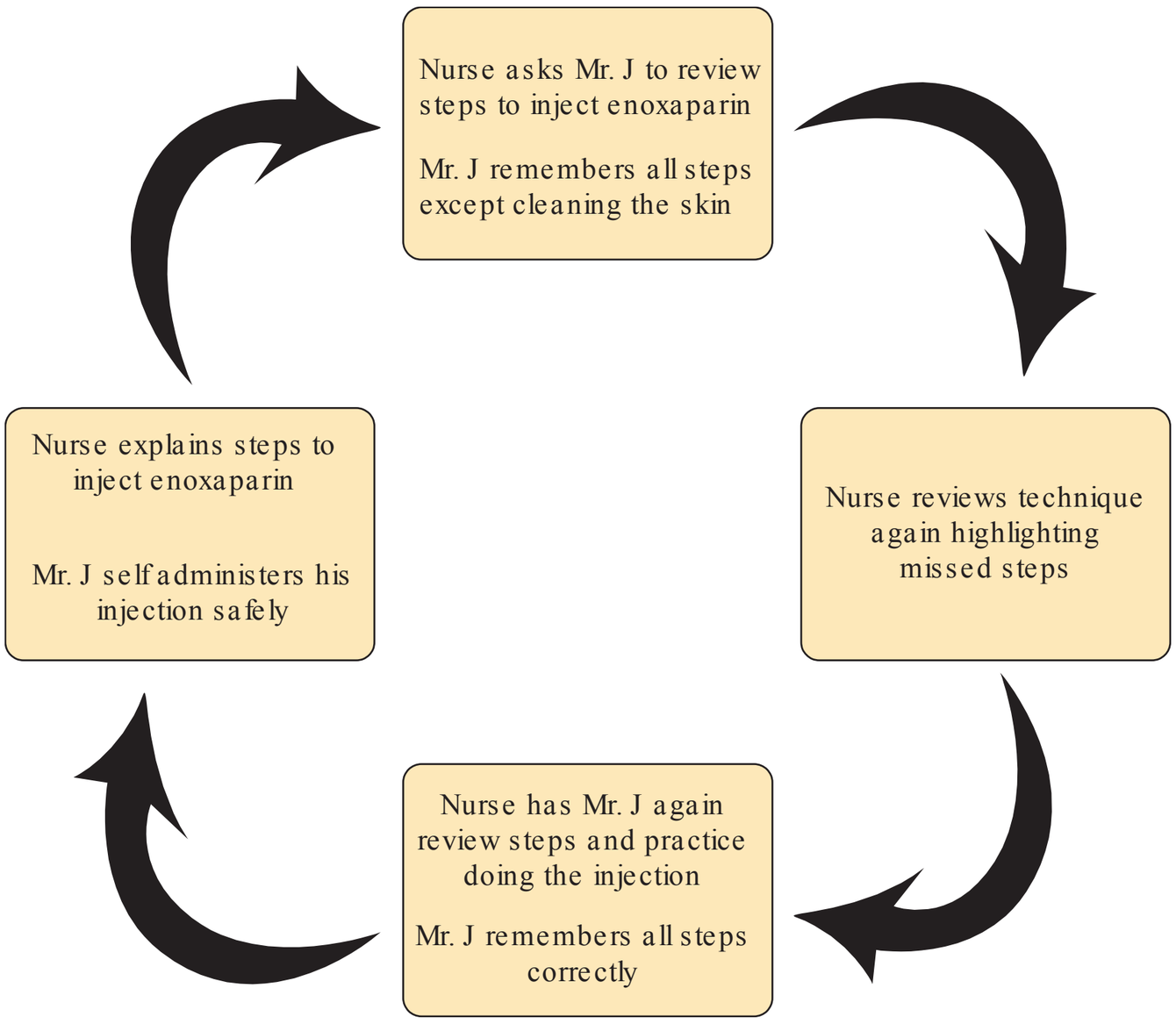


Figure 15-1. Practicing closing the loop.

DISCUSSION QUESTIONS

1. Consider a patient you recently worked with. Identify the literacy challenges she may have faced during the encounter and in her attempts to follow up on your recommendations.
2. Discuss how you will integrate two communication strategies introduced in this chapter into your next patient interaction.
3. Describe one thing that you would change about your health-care system or organization to make it a more health literate health-care organization.

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Chapter 16

Group Medical Visits for Underserved Populations

Pooja Mittal, DO, Hali Hammer, MD, and Margaret Hutchison, CNM

Objectives

- Define the group medical visit.
- Review the most common group medical visit models.
- Discuss the advantages of group medical visits, particularly for underserved populations.
- Describe some of the obstacles to establishing group-based models of care in safety-net health settings, at the clinic, provider, and participant levels.

Liu Su Chen is a 72-year-old woman with type 2 diabetes, hypertension, and osteoarthritis. Mrs. Chen neither speaks nor reads English. Mrs. Chen's diabetes is now poorly controlled. Consultations with a nutritionist and diabetes educator have had little effect on her glycemic control. She is now on maximum doses of oral diabetes medicines and medications for other chronic medical problems. When her doctor begins the discussion of adding insulin treatment, Mrs. Chen becomes visibly upset. "I only know one person who has taken insulin for her diabetes, and she died within a year of starting the shots!" she says. A colleague of Mrs. Chen's physician recently began offering diabetes care to groups of 8 to 15 patients in Cantonese and English and she wonders if those visits might help her patient.

INTRODUCTION

Efforts to reform ambulatory care have focused on optimizing access to care while making efficient use of limited resources. This chapter describes the group medical visit (GMV), an approach that is gaining widespread acceptance and has been studied in diverse health-care settings and patient populations. Both the advantages and challenges of providing group-based care, particularly among underserved populations, are reviewed.

WHAT IS A GROUP MEDICAL VISIT?

Mrs. Chen's doctor convinces her to attend one of the new group medical visits by pointing out that she may meet other people who are taking insulin, and that everything will be presented in her language.

Many different models of group-based care have been developed, each tailored to the specific population served. Most of the existing models of group-based care were developed in managed care or academic practice settings. The GMV has taken a variety of names, such as the "cluster visit,"[1] "chronic care clinic,"[2] "shared medical appointment/drop-in group medical appointments,"[3] "cooperative health-care clinic,"[4,5] and group prenatal and early parenting visits trademarked as "CenteringPregnancy®" and "CenteringParenting®"[6] All of these groups have been implemented as a means of improving the quality of care, the patient care experience, and access to

Box 16-1. Components of Group Medical Visit Models

- Peer support and community building included in the clinical encounter.
- Point-of-care collaboration by an interdisciplinary team.
- Interactive group learning.
- Focus on self-management and self-efficacy.

care when compared with the traditional brief, one-on-one clinical encounter (see Box 16-1).

A GMV is a clinical encounter typically organized and run by a team that includes a provider (physician or advanced practice clinician) plus another member of the health-care team and is comanaged by the participating patients. Most GMVs target patients with a common health concern, such as concerns around aging, a particular chronic illness, pregnancy, or early parenting/well-child support. GMVs offer routine medical care, support, and learning. Some GMVs meet more frequently than usual individual visits (typically monthly to quarterly); most GMVs involve a stable membership of 8–25 patients, and last from 90 minutes to 3 hours. GMVs can be structured either to supplement or to replace individual patient visits (see Box 16-2).

Table 16-1 presents a rough outline of a GMV format. Most models include elements of group time—"check-ins," goal setting, learning—as well as one-on-one time for each participant with the group's medical provider to tend to medical aspects of care. GMV models with continuity of participants over a series of visits may have an intentional focus on community building, out of appreciation that social support can be an important determinant in health outcomes.[7]

Box 16-2. Elements of the Group Medical Visit

- Must include a provider who can bill for services to ensure financial sustainability.
- Most commonly, groups are co-led by a team of a provider and other health-care team member, such as an RN, a health educator, a nutritionist, a social worker, a medical assistant, or a community health worker.
- Participating patients are often actively involved in management of the group.
- May replace the one-on-one medical visit or be supplemental.
- All GMV models include some element of facilitative leadership, to encourage peer-to-peer learning, participant engagement, and empowerment.
- The medical provider component of the GMV can include limited physical examination and medication prescribing/adjusting.

MODELS OF GROUP MEDICAL VISITS

The following are brief descriptions of different kinds of GMV models. In the descriptions, "provider" refers to the health-care provider who can bill for services (physician or advanced practice clinician).

COOPERATIVE HEALTH-CARE CLINICS

Cooperative health-care clinics were developed by John Scott and colleagues at Colorado Kaiser Permanente Medical Group. The primary goal of this was to decrease unnecessary emergency department and urgent care use, initially among elderly patients.[4,5,8] These monthly GMVs are cofacilitated by a provider and a nurse for a targeted group of 20–25 patients. Each cooperative health-care clinic includes group education, social time, one-on-one contact with the provider and/or nurse, and an opportunity for questions and answers. Cooperative health-care clinics also have been used in specialty settings with patients with diabetes or stroke. Typically, cooperative health-care clinics replace the individual encounter or decrease the frequency of one-on-one visits. One study demonstrated decreased outpatient and emergency utilization of care.[9]

DROP-IN GROUP MEDICAL APPOINTMENT

Drop-in group medical appointments target all of the patients on a busy provider's panel (i.e., a medically heterogeneous group of patients) rather than patients who share a common medical problem or characteristic (as in cooperative health-care clinic). Developed by Edward Noffsinger at the San Jose, California, medical offices Kaiser Permanente Northern California, drop-in group medical appointments increase patients' access to their provider by opening up extended appointments that they can use as often as they choose.[10] Usually co-led by a provider and a behavioral health professional (psychologist, social worker, health educator, or therapist), drop-in group medical appointments provide the opportunity for more holistic health care than is typically provided in an individual clinic visit. By seeing many patients simultaneously, drop-in group medical appointments have been successful in easing time constraints commonly imposed on both primary and specialty care practices. Drop-in group medical appointments usually use a nurse and a behavioral health clinician to maximize the impact of the visit for the patient.[11]

Table 16-1. Sample Group Medical Visit Format

Time (min)	Activity	Content
15–60	Preparation prior to group session	Chart prep, planning the session content, setting up the space (chairs, food, music, materials)
15–45	Check-in	• Participants arrive; vital signs are obtained and recorded • Some GMVs include individual follow-up related to goals set in previous session
30–75	Group learning	• May begin with an opening activity • Trained facilitators lead discussion(s), determined by group needs; some models include specific agendas for each session • Facilitation supports group process, participant sense of empowerment, and community building • Written educational materials and other visual aids may be used
30	One-on-one	Medical providers or a group facilitator meets briefly with each participant for a one-on-one assessment; components of this assessment can include: • Check-in on issues specific to participant not addressed in group • Focused physical examinations • Refilling prescriptions and ordering referrals, laboratory tests or treatments as indicated • Establishing whether there is a need for private examination, generally soon after the GMV • In some GMV models (i.e., Centering) the one-on-one assessment occurs during the individual check-in time, after vital signs are obtained and recorded for the participant
5–30	Closing group session	• In some GMV models, closing includes question and answer time plus individual private examinations (10 minutes maximum per exam); if private exams occur, other group members might socialize or leave. • In other models, closing time is shorter and is focused on a closing group activity
15–60	Wrap-up after session ends	• Close group space, debrief of session by group facilitators (how did the session go?), plan for follow-up of session, plan for next session, completion of charting • In some GMV models, this time also used for any needed brief private physical examinations/ consultations

Note: This table provides a guide to the flow of the chronic disease and Centering group medical visit models, with an overview of the components and activities that might occur during a typical 2-hour group session. GMV = group medical visits
Source: Adapted from Miller D, Zantop V, Hammer H, Faust S, Grumbach K. Group medical visits for low-income women with chronic disease: A feasibility study. J Womens Health (Larchmont) 2004;13:217-225, and Centering Healthcare Institute model implementation materials.

CHRONIC CARE CLINICS

Chronic care clinics (CCCs) are periodic primary care sessions organized to meet the complex needs of patients with chronic conditions to improve outcomes. These have been used for patients with diabetes, congestive heart failure, and geriatric patients. They are planned clinical encounters for targeted patients with a specific medical condition in a primary care setting.[2] Based on the "mini-clinic" developed in general practices in the United Kingdom, the CCC is a half-day–long session that includes a stable cohort of 8–12 participants. Sessions include brief one-on-one visits with a primary care provider and can include involvement of other clinic staff and providers (such as pharmacists). Each session also includes group education and discussion. These clinics focus on the need for active patient participation and support patients' confidence and skills in managing their illness. CCCs typically occur three to four times per year and supplement the regular one-on-one visit.

CLUSTER VISITS

Cluster visits are directed at patients with a particular chronic illness, most commonly diabetes.[1,12] These are monthly GMVs of 10–18 patients for a finite period of time, usually 6 months. They are led by a specially trained nurse educator, and supported by physicians and other clinicians who are readily available for consultations. There are referrals to nutritionists, behavioralists, pharmacists, and social workers. Some cluster visits use a multidisciplinary team led by a nurse educator and include a dietitian, a pharmacist, and a behavioral therapist. The cluster visit model, which was developed at Kaiser Permanente, incorporates nurse care management, including frequent telephone follow-up between visits, coordination of needed ancillary services, and intensive medication management. In contrast to the models previously described, cluster visits replace usual primary and specialty care for the targeted chronic illness during the intervention period.

GROUP PRENATAL VISITS

A GMV called CenteringPregnancy[6,13] has emerged as the most promising model for group care during pregnancy, with strong evidence to support its efficacy and appeal to participants. In this model, a cohort of 8–12 pregnant women, whose babies are due in the same 1–3-month period, meets as a group beginning in the early second

trimester and continuing through 40 weeks of pregnancy. Each session is co-led by a consistent team made up of an obstetric provider and another member of the perinatal services team. During each 2-hour group session, women (and sometimes support people) participate in self-care activities, group discussions on topics related to pregnancy, childbirth and parenting, community-building activities, and routine physical assessments by the obstetric provider. After initial entry into prenatal care, these group sessions replace one-on-one prenatal visits, with 10 group visits over the course of pregnancy. Multiple studies, including a randomized controlled trial, demonstrate improved health outcomes, knowledge among participants, and satisfaction with care when compared with one-on-one prenatal visits (see section "Improved Care Outcomes").

GROUP WELL-CHILD VISITS

Group well-child visits were one of the first models of GMVs in the United States.[14,15] In most settings, the group well-child visit is a primary care visit in a group setting and replaces the usual periodic well-baby visits in the first year of life (newborn, 2, 4, 6, 9, and 12 months). With an emphasis on age-specific anticipatory guidance and group support for parents of infants of the same age, these visits minimize the repetition inherent in well-child care and also are an efficient way for providers to provide routine primary care. One study noted that participating mothers recognized several benefits of group well-child visits, including (1) support from other women, (2) opportunities to make developmental comparisons with other infants, (3) the chance to learn from other participants' experiences, (4) enhanced parental involvement in the visit, and (5) more time with the provider.[16]

MOTHER–BABY DYAD CARE

Another centering group care model is CenteringParenting, a mother (or other caregiver)/infant dyad model. Typically, there are six caregiver/infant dyads, or 12 patients, in each cohort. Groups meet beginning in the early neonatal/early postpartum period (around 2 weeks of the baby's life), and continue through at least the first year of the baby's life. As in CenteringPregnancy, these groups replace individual care visits, in this case both for the woman and for the infant. In some settings, groups transition seamlessly from CenteringPregnancy to CenteringParenting, thereby building on the relationships formed and group learning achieved during the prenatal period. Each group visit addresses the physical health of both mother and infant, as well as offers a setting where parents build on their collective knowledge about caring for their babies. Activities during the group visits are tailored to the specific needs of the dyads; for example, the Edinburgh Postpartum Depression Scale is employed in the early infancy period to facilitate discussion of stress, support, and self-care for mothers.

BENEFITS OF GROUP MEDICAL VISITS IN UNDERSERVED POPULATIONS

> Mrs. Chen has few friends or family members who have diabetes, and no close acquaintances who use insulin injections. At the first group medical visit appointment, she is interested to hear another Cantonese-speaking woman talk about her experience of initiating insulin therapy, and how much better the woman had felt after she learned to give herself injections and her blood sugar levels improved.

Although many GMV models were developed in managed care settings, others have taken a firm hold in public health settings. For a summary of benefits of GMVs with underserved populations, see Box 16-3.

SOCIAL SUPPORT

Support groups for patients with chronic illness have been studied in a number of different settings, and group support has been shown to improve patient satisfaction and psychosocial outcomes.[17,18] Moreover, support groups are effective in diverse patient populations. Individuals with chronic illness express satisfaction and show improved self-management practices when they interact with others living with the same condition. Also, there is the opportunity to discuss psychosocial sequelae of their illness (sexual dysfunction, social isolation, disability, depression, changes in body image), which is less likely to occur in the brief individual visit with a health-care provider who has not experienced similar problems and who is not a peer. The simple process of identifying oneself with another individual in the group can have a powerful effect, especially when there is isolation or confusion. In

Box 16-3. Advantages of the Group Medical Visit Model for Socioeconomically Disadvantaged Patients

- May alleviate access issues common in low-resource settings.
- Designed to mitigate the challenges of language and literacy.
- Potential to more effectively promote self-efficacy and positive behavior change.
- Opportunity to develop community and gain social support from a peer group.

addition, GMV participants have a sense of accountability to other members of the group or discover that sharing their personal experiences may be of help to others, either of which may promote positive behavior change and healthy practices. The social support aspect of group visits may reinforce a patient's self-efficacy, leading to positive health behavior change.[19] In pregnancy, positive social support and self-esteem may provide a sense of mastery and reduce feelings of helplessness.[20]

IMPROVED CARE OUTCOMES

There is growing evidence that GMVs are associated with improved care outcomes. Research has shown that diabetes care in a group setting can result in greater reductions in A_{1C}[21] as well as improvements in blood pressure and weight loss.[22] There is also evidence that GMVs can prevent worsening of A_{1C}.[23] In a systematic review of the evidence, GMVs resulted in improved patient and clinical outcomes.[24]

The data from a randomized controlled trial of CenteringPregnancy®is impressive: women assigned to GMVs, when compared with women receiving individual care in the same system, had significant decreases in preterm births, better prenatal knowledge, felt more ready for labor and delivery, and had greater satisfaction with care.[25] In addition, breastfeeding initiation was higher in the CenteringPregnancy®groups compared with standard care. Facilitative leadership plays an important part in these outcomes. Novick et al found that maintaining fidelity to the facilitative group processes (i.e., maintaining patient engagement) in CenteringPregnancy®had a positive association with reductions in preterm birth and in intensive utilization of care.[26] We expect to see continued evidence regarding the benefits of group care, not only for provider time savings but also for improved care outcomes.

JUDICIOUS USE OF HEALTH-CARE RESOURCES

> Mr. and Mrs. Chen have noticed that their doctor seems increasingly rushed, and the clinic more busy. They usually get about 10 minutes of the doctor's time, much of which is spent working through an interpreter, and it often takes months to get a follow-up appointment. Previously, this was not such a problem because Mrs. Chen could always see the diabetes nurse case manager when she had a diabetes-related problem and could not get to see her doctor. Now, the clinic has no nurse assigned specifically to diabetes care.

GMVs have the potential to lead to more efficient use of limited health-care resources. Studies that target high users of health care show decreased hospitalizations and emergency department use after GMV attendance.[1,4,5] Similarly, pilot data on CenteringPregnancy showed a decreased use of the emergency room between visits by pregnant participants doing centering when compared with women doing one-on-one care.[6] These outcomes may be explained by the increased knowledge base of participants of GMVs, which includes an increased understanding of how to differentiate between normal and abnormal conditions and self-management skills useful to address common issues before they become urgent problems. For example, most chronic illness groups employ patient education materials based on "stop signs," color-coded guides for patients with asthma, diabetes, and congestive heart failure. These materials use objective (e.g., blood sugar, peak flow) and subjective (e.g., non-healing foot sore, poor response to nebulizer therapy) measures to tell patients when to seek professional attention. Instruction in the use of such tools, as well as guiding parents and pregnant women about when to go to the hospital or emergency room can be done as easily and perhaps more effectively in a group setting than in individual visits. Further support of positive health behavior change—including more appropriate use of the health system—can be hypothesized to result from an increased sense of self-efficacy and empowerment supported by some group models.

LANGUAGE AND LITERACY

> The Chens' primary care provider is a monolingual English-speaking family physician. Mrs. Chen relies primarily on her 78-year-old husband and occasionally a hospital interpreter to interpret all of her medical interactions. Mrs. Chen now finds herself much more engaged during her group appointments because she can understand everything that is being said by the doctor and health educator, and does not need to rely on translation. She also finds that she learns a lot about her diabetes from her peers because they use language (colloquial expressions or idioms) and express challenges that she understands.

Language barriers and low functional health literacy are associated with poor quality of care for patients with chronic illness.[27,28] Non–English-speaking patients have poor access to language-concordant health education materials and health-care providers, lower satisfaction with care, lower knowledge of their medication regimen, poor self-management, and worse health status (see Chapters 15 and 31). In addition, language discordance between primary care providers and patients is associated with poor self-reported interpersonal processes of care,[29] and in diabetes, with poor glycemic control.[30] Through GMVs, language access can be achieved much more efficiently either through the use of bilingual providers and/or cofacilitators, or by use of a single interpreter

who interprets for all group participants at one time. Patients with low health literacy report difficulties with many aspects of communication in the health-care setting, including worse comprehension of both written and oral communication. Group-based care has the potential to diminish these barriers through tailoring educational approaches to the literacy needs of a group of participants. There is some evidence that GMVs tailored to the language and literacy needs of participants lead to significantly higher levels of engagement among traditionally hard-to-reach patients.[31]

EXPANDED ROLE OF FAMILY MEMBERS AND OTHER SUPPORT PEOPLE

> Mr. Chen has never been satisfied with his role in helping his wife live with diabetes. He feels useful when he serves as her interpreter, but does not feel like he can ask his own questions of the doctor. He enjoys the group visits because there are other family members without diabetes who come to the groups, and he has now identified ways to best help his wife, such as supporting her self-management goals and drawing up her insulin syringes.

Usual ambulatory medical practice has little role for close family members in the care of pregnant women or individuals with chronic illness. Except in the case of parents of children with asthma and other chronic disease, partners and other primary caregivers are rarely actively engaged in treatment plans. In many settings, GMVs invite participation of each patient's family members or primary support people out of awareness of their importance to the health of the patient. Participation of support people may include engaging them in their own health-related goals as well as their role development as caregivers or coparents.

SELF-MANAGEMENT, SELF-EFFICACY, AND EMPOWERMENT

> Mrs. Chen usually leaves her doctor's appointments with a clear understanding of what medications she should take and what her doctor thinks she should be doing to keep her blood sugar under control, such as limiting sweets or starches and exercising regularly. She keeps those things in mind for the first day or two after the visit, but loses track of them during the months that elapse between appointments.

Problem-focused one-on-one consultations with a provider, occasionally supplemented by educational sessions with ancillary clinicians (nurse educators, pharmacists, nutritionists), are the mainstay of traditional ambulatory care. This may be an ineffective and inefficient model for implementing the lifestyle changes so important for management of chronic medical problems and for promoting wellness. Practitioners have only recently begun to realize that successful chronic illness management relies as much on having an active patient "self-manager," as it does on an "active provider" choosing the right medications or other treatment.[32-34] The traditional practice of imparting medical information and imploring the patient to make significant lifestyle change is often so clearly in conflict with normal daily living that it is ignored or forgotten. Moreover, traditional health education is limited in its ability to account for cultural or environmental influences on health behaviors.

There is a movement in health education toward a participatory approach.[35] This involves patient-directed discussion of what is possible in terms of lifestyle changes, followed by patient-determined goal setting.[32] Ideally, goal setting is done in the context of a continuity relationship with a provider or other health-care professional so that the discussion of goals for lifestyle change is ongoing and dynamic. By bringing this discussion into a facilitated group session, there is an opportunity to problem-solve together with peers that can decrease the sense of isolation, both socially and in the context of a patient's particular medical condition or struggles. Unfortunately, most providers and health-care staff are not trained in facilitation, self-management education, or participatory learning; most are trained to relate to patients in a didactic expert–learner model. A benefit, therefore, of the GMV is the opportunity it provides for medical staff to move into a new kind of relationship with patients, one that has a potential to be more satisfying for all.

FACILITATOR LEARNING: WHAT GMVS TEACH GROUP LEADERS

GMV models often provide a fertile ground for both providers and other staff to learn about themselves, about their clients, and about new ways of providing care. A group model that has a focus on empowerment and on breaking down the divide between "patient" and "expert" facilitates creation of a group environment where participants feel comfortable sharing what's important in their lives, and pushes group leaders to examine their own sense of what is important in a medical visit, that is, who sets the agenda for the medical visit. Commonly, group leaders who engage in this process report that what they learn in the group setting informs their other health-care interactions (one-on-one), as well as their personal relationships. Finally, in settings where there are trainees or learners, group care provides an excellent educational opportunity.

CHALLENGES IN IMPLEMENTING GROUP MEDICAL VISITS FOR UNDERSERVED POPULATIONS

The current dominant approach in medicine views the provider as the "expert" in the health-care interaction and the patient a passive follower. The national health-care reform conversation has put the concept of "patient-centered care" at the forefront, with a primary focus on how we can promote this concept within the constraints of the traditional one-on-one medical encounter and within our traditional outpatient structures of care.

CULTURE OF CARE

Because of both the structure of GMVs—no wait times, shared engagement in health information and planning—and because of the effort in some GMV models to move out of the didactic and into the facilitative model, group care can represent a significant change in what is currently the culture of medical care. In facilitated GMVs, participants come to realize their potential for making positive changes in their own health.[36] This shift can be difficult for the provider and often requires an adjustment of their role in the care of the patient. Furthermore, some patients may prefer a hierarchical or passive relationship with a medical provider, and may resist more participatory approaches to their own care.

PARTICIPANT RECRUITMENT AND ATTENDANCE

GMVs, though more common, are still a new concept for many potential participants. Consequently, it is often challenging to "sell" the group model. Some fear that GMVs are lower quality care, and/or a cost-saving effort; some patients have had negative experiences in other types of groups; and some may see groups as a "class," and therefore potentially of lesser value than a medical visit. An additional challenge to recruitment efforts is the buy-in that is required throughout a system to make group care appealing to patients, since all parts of the system can influence their decisions about the kind of care they receive. Some sites, particularly with the Centering model, have found that having an "opt-out" group care model (i.e., GMVs are the norm but patients can opt out) is what leads to sustainability and success, because the messaging for patients is simplified and the group care model is viewed as integral to the clinic. Once patients attend their first group session, the responsibility then shifts to the group leaders to create an environment that makes participants wants to return.

There have been reports of low recruitment rates for GMVs in socioeconomically disadvantaged populations.[37-39] In contrast to the older, privately insured patients originally targeted by GMVs, uninsured or underinsured patients are more likely to have challenges associated with poverty that make attendance at any medical visits difficult. These may have to do with mental health and/or substance abuse issues, lack of social support, inflexible workplaces, caregiving responsibilities, or transportation. Efforts to address these challenges may include incentives for participation or attendance, healthy snacks, on-site child care, transportation vouchers, and health-related "giveaways" such as exercise bands, pedometers, and recipe books.

CHANGE

There is a body of literature about change and how difficult it can be, especially in complex, low-resourced systems. Thus, the actual change of the system of care—creating a new way of doing business that is sustainable—is often the most challenging part of implementation of new programs. Because group visits are a significant shift in the care model, as well as in the culture of how care is delivered, the systems change required is significant. Examples of the various changes that need to occur include scheduling appointments, scheduling provider and support staff time, billing, space issues, and provider and staff behavior. For this reason, the shift to group visits can only be successful with buy-in throughout an organization. Caldwell et al described how the readiness for change and the quality of leadership directly impact patient satisfaction in an evolving system.[40]

SPACE

Ambulatory care practices, which are designed for individual visits, are challenged by the practical arrangements required to accommodate group visits. The main obstacle for many practices in planning GMVs is the lack of available rooms large enough to accommodate 8–25 people. Although space is limited in many ambulatory care settings, public health clinics may have even more severe space constraints, and academic centers in particular struggle with competing needs for space for educational activities. As clinics remodel, practices that include the GMV often build a new kind of clinic space that includes group visit areas. While having a dedicated group space is ideal (both from a sustainability and a patient care perspective), sites often work out arrangements internally for shared use of an appropriate space.

TRAINING FACILITATORS AND MODEL IMPLEMENTATION

Training in group facilitation and participatory learning is essential to the success of GMVs because of the complexity or difficulty of change at both the systems level and the

individual practice level. For individual group visit co-leaders, the GMV calls on a different skill set than individual care, and these skills need to be taught as an integral part of roll-out. Optimal training and implementation can be challenging in many health centers, especially those that are publicly funded and under-resourced. Furthermore, if the GMV is seen only as supplemental or nonessential, it may not be prioritized when making staffing decisions and when considering investments in change.

There are various resources to support the implementation of GMVs; implementation can include both system redesign and staff training. One example is the Group Visit Facilitators Training Manual and Protocol of the Improving Diabetes Efforts Across Language and Literacy (IDEALL) project at San Francisco General Hospital (see no. 4 on the resource list). Another example is the Centering model; implementation of Centering is supported by engagement with the Centering Healthcare Institute, a nonprofit organization that oversees the development of Centering across systems. For more information about implementation and training, see the GMV resource list at the end of this chapter.

PERSONNEL

Safety-net systems are often leaders in innovation, while also challenged in terms of resources. Development of a successful GMV requires both vision and resources, requiring a minimum training for all GMV team members as well as explicit articulation of roles. This kind of systems change requires that all members of a clinical area be engaged in the change, as all are impacted by the GMV and have a role to play in its success. For example, even though the scheduling clerk will not directly participate in the group visit, s/he will be involved in creating the group scheduling template and may also have an important role to play in encouraging participants to enroll in and attend group. Negative feelings about the GMV among staff in a clinic can influence model sustainability and should be explored and addressed. Again, leadership buy-in is essential.

SCHEDULING

GMVs can be difficult to incorporate into traditional clinic schedules, as the templating of appointments is often unique and different from how other appointments are made. If the benefits of GMV are not apparent to frontline clinic staff, there can be resistance to making the necessary changes to existing schedules. In groups that are multidisciplinary, this adds another layer of complexity to schedule groups across different provider types. This is particularly true in a training setting where trainee schedules are complex and, at times, unpredictable.

CONFIDENTIALITY

Maintaining confidentiality is one of the main concerns expressed when group-based care is first introduced to health-care professionals. The fear is both that patients will not disclose important health information because of the lack of privacy and that a group model may not be compliant with privacy regulations. Interestingly, qualitative analysis has shown that very few patients report concerns about confidentiality within the group model as a barrier to participation.[39] The Health Insurance Portability and Accountability Act of 1996 (HIPAA) protects involuntary disclosure of medical information without the written permission of the patient, and consequently many GMV facilitators ask participants to sign a confidentiality statement at the onset of the GMV.

ADDITIONAL CONSIDERATIONS

GROUP DIVERSITY

Populations served in public health settings tend to be very diverse in terms of health literacy, levels of education, ethnic and/or cultural identity, language, and class (among other variables). These differences can make designing a suitable group intervention a challenge, and require that leaders actively facilitate group interactions to create a safe space for all participants. Group- and peer-based care may not always meet the needs of every individual in the group, and therefore the role of group leaders can include providing some individual attention to those who might fall on either end of the spectrum (either higher or lower literacy than the group). In spite of the challenges inherent in diversity, groups also provide an opportunity for participants to connect and bond on the commonalities they share: for example, in group prenatal visits, all are women who will soon have babies. There is now a precedent for GMV models tailored to the education, language, and health literacy needs of the subpopulations served in public health settings.[41-43] Table 16-2 is an example of a tool that can help leaders assess their groups, thereby supporting the leaders' personal growth as facilitators as well as assisting in planning for future group sessions.

IMPACT OF MENTAL HEALTH COMORBIDITIES

Psychiatric comorbidities are more common among those with chronic illness. Among patients with diabetes alone, depression is three times as common as it is in the general population. Most chronic illness groups address psychological problems related to the illness and other psychosocial issues. In some public health settings,

Table 16-2. Facilitator Process Evaluation Form for Group Prenatal Visits

Facilitator Process Evaluation			
Facilitator's Names	Date	Session No.	
Number of participants:	Moms:	Support Persons:	
Environment and Session Activities	Poor	Fair	Good
On-time start and finish			
Women measure and record weights for themselves			
Women measure and record their own blood pressure (if applicable)			
Exams completed within the first 30–40 minutes of the session			
Quality of Group Dynamics and Facilitation	Poor	Fair	Good
Core content discussed with a facilitative approach			
Sharing of information, ideas, feelings, or experiences among participants			
Group members demonstrate understanding of educational content			
Session felt more like a "peer group" than a "classroom"			

Source: Used with permission from Centering Facilitator Guide, Centering Healthcare Institute.

cognitive-behavioral GMVs are being offered for patients living with chronic illness.

The psychological aspects of pregnancy and parenting are addressed in both CenteringPregnancy®and CenteringParenting®, out of recognition of their impact on healthy family formation. Psychiatric conditions may present a challenge to group facilitation and to community building if the conditions have a negative impact on the group function; this is primarily an issue with personality-disordered participants. In contrast, participants with trauma, anxiety, and/or depression may benefit greatly from the group and may be very active and engaged participants. Because mental health can impact both individual group members as well as the group as a whole, part of facilitation training should include training in "facilitation challenges," including those related to participants with mental health comorbidities.

PATIENT MATERIALS

Some group care models require the use of materials (such as self-administered blood pressure machines) or educational supplies (such as "Mom's Notebooks" used in Centering) that are not currently available in a clinic setting. For groups to be sustainable in a system, these kinds of supplies must become part of a clinic's budget, often a challenge for under-resourced public facilities.

COST

Few studies to date have shown that group-based care is cost-effective.[1,4,5,25] Moreover, there is a great deal of uncertainty about reimbursement from publicly funded payers, which varies from state to state. Reimbursement for group-based prenatal care may be more consistent than for chronic illness groups because of the precedent in prenatal care for payment for ancillary medical services. There is no billing code specifically for group-based care. Most practices that have successfully billed for group-based care have done so by using visit codes for the face-to-face time spent directly with the provider. However, it is notable that most of the GMV models were developed and continue to be most widely used in closed health maintenance organizations (e.g., Kaiser Permanente) where there is little outside billing for clinical services. These integrated systems are also in a better position to realize the cost savings associated with improved health outcomes and behaviors.

- The extent of buy-in necessary within a system to make a group care model sustainable is time consuming and sometimes challenging to attain.
- Health clinics were generally not built with group care in mind, and finding suitable space can be challenging.
- Recruitment or enrollment of participants may be difficult because of the challenges inherent in "selling" a care model that is not familiar to patients; there may be a perception that group care is substandard.
- Many clinics feel unable to invest in group care, that is, in necessary staff resources, systems redesign, and facilitator training.
- It is difficult to make a business case for group visits both because of inadequate data on cost-effectiveness, and because potential savings (e.g., related to improved health outcomes) may not be realized at the clinic level.
- Most providers and staff do not have group care and group facilitation skills, and, without training and support, commonly fall back on didactic care provision.

CONCLUSION

Six months after she started attending the GMVs, Liu Su Chen is using insulin to control her diabetes. She enjoys the social interaction so much that she has joined an exercise group at her neighborhood senior center. She is even considering undergoing training so that she can be a peer leader for a "Living with Chronic Illness" support and education group starting at her church.

Group-based ambulatory care is a feasible and effective alternative to the traditional one-on-one encounter. Participation in GMVs leads to improved clinical outcomes and is associated with high levels of satisfaction for both patients and providers. In this era of increasingly limited healthcare resources and providers with less time and more demands constraining their clinical encounters, GMVs are an exciting example of redesigning ambulatory practice to meet the unique needs of diverse patient populations.

- GMVs are an innovative approach to providing care.
- Many different GMV models exist.
- All GMV models incorporate health education, self-management, peer support, and medical care.

Guidelines for Empowerment-Based Facilitation

When you facilitate, you are balancing the ideas and opinions of the various members, so the conversation will flow and the discussion will be productive. Awareness of the following issues and how you address them during your groups will lead to greater patient empowerment.

1. Create a psychologically safe (accepting, uncritical) environment for personal reflection and sharing.
2. Communicate effectively. Clarify ideas within the group to foster dialogue, learning, and decision making.
   - Repeat remarks made by various speakers.
   - Define ambiguous words or ask the group to define them.
   - When it is not necessary for you to answer a question asked, throw it back to the group.
   - Ask participants for suggestions on how the discussion should continue, and present a few ideas based on observations of how the dialogue is progressing.
   - Keep the conversation on track by asking "why" and "how" questions.
   - Summarize the ideas mentioned.
3. Accept your role as a provider, educator, or facilitator, not group therapist. You are there to guide the groups and encourage participants, not to solve every participant's problems.
4. Balance the needs of talkative and shy group members, respectively. Ensure that every participant has an opportunity to speak. Balance the needs of talkative and shy group members by asking open-ended questions.
5. Foster understanding. In spite of disagreements within the group, you must encourage participants to accept (not necessarily agree with) differing points of view; highlight agreements made, and point out differences. This is the only way a productive discussion can take place.
6. Provide an opportunity for patients' significant others and family members to express opinions or concerns.
7. Guide discussions to stay focused on course objectives. To increase the exchange of ideas and communication within the group, in addition to personal experiences, suggest other methods of discussion, such as brainstorming, small group–large group discussions, writing, performing, flip chart, or silent reflection. The goal is to increase each participant's self-awareness, foster skills such as goal setting, and enable each patient to plan and carry out self-directed behavior changes.

Source: Adapted from Arnold MS, Butler PM, Anderson RM, Funnell MM, Feste C. Guidelines for facilitating a patient empowerment program. Diabetes Educ 1995;21:308-312.

DISCUSSION QUESTIONS

1. Considering what you know about Mrs. Chen and her medical problems, make a list of some possible topics for group discussion for a GMV in which she is enrolled.
2. Describe a patient whom you have encountered who would benefit from group-based care.
3. If Mrs. Chen were your patient, how would you talk to her about the GMVs in such a way to convince her to give it a try?
4. Discuss some of the potential challenges to instituting CenteringPregnancy®or Parenting in some of the ambulatory care settings with which you are familiar.
5. Do you think group-based care is a replacement for usual care, or an adjunct? Discuss the circumstances in which you might feel one way or another.

RESOURCES

Action Plan Project of the UCSF Collaborative Research Network: www.action-plans.org

Centering Healthcare Institute: www.centeringhealthcare.org

Improving Chronic Illness Care. Group visit starter kit. Available at www.improvingchroniccare.org/improvement/docs/startkit.doc

Improving Diabetes Efforts Across Language and Literacy (IDEALL) Project. Group visit facilitators training manual and protocol. San Francisco General Hospital, San Francisco, CA. Available at www.cmwf.org/tools/tools_show.htm?doc_id=228393

Institute for Healthcare Improvement. Continuing care clinic handbook. Available at www.ihi.org

Lorig K, Holman HR, Sobel D, et al. Living a Healthy Life with Chronic Conditions, 2nd ed. Palo Alto, CA: Bull Publications, 2000.

Group Visit Guide: http://www.massgeneral.org/stoecklecenter/assets/pdf/group_visit_guide.pdf

A Qualitative Review of Current Research: http://www.jabfm.com/content/19/3/276.full

Noffsinger Group Visit Blog/Website: www.groupvisits.com

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Chapter 17

Applying Interactive Mobile Health (mHealth) Technologies for Vulnerable Populations

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Objectives

- Describe the rationale for using interactive mobile health (mHealth) technologies as an adjunct to the care of socioeconomically vulnerable patients, both in the United States and abroad.
- Review potential uses of mHealth in chronic illness care.
- Review the evidence for the effectiveness of mHealth in chronic illness care.
- Describe the characteristics of patients best suited to use mHealth as part of their care.
- Review the use of mHealth as a method of improving communication between providers of health care (inpatient and outpatient; community and health system).

Jason, a patient with active human immunodeficiency virus (HIV) and occasional cocaine use, has difficulty adhering to the multi-pill HIV regimen. He enrolls in a novel web-based program in which he is equipped with a text pager that reminds him when and how to take his medications and prompts him to enter simple adherence data. If he does not respond or reports poor adherence, his case manager attempts to connect with him either in person or by phone. Several months after enrollment in the program, his viral load drops to the undetectable level.

Innovative methods to educate patients and providers, promote adherence, and enhance communication both between patients and providers and among providers across different settings have become available through the growth of computer-based technologies. Interactive web- or mobile phone-based programs are often broadly referred to as mobile health or "mHealth," a term that we will use here to encompass any patient-facing computerized health technology. Examples of mHealth include systems that monitor patients' progress toward physical activity goals, assess risk of disease, remind patients to take medications, or provide the information patients need for more informed decision making. While most patients with chronic diseases struggle with self-care, innovations such as these may have the greatest impact on improving the care of vulnerable patients, who often face barriers to accessing health information and support via face-to-face encounters with clinicians and other helpful social network members.

Access to the Internet is becoming commonplace. Recent surveys by the Pew Research Center report that 85% of Americans use the Internet and 91% have mobile phones (including 56% who have smartphones with Internet access).[1] Most importantly, the differences in Internet and mobile phone use by race/ethnicity and socioeconomic status have been shrinking rapidly. Similarly, there has been an explosion in the use of mHealth technology in health-care settings, such as the introduction of personal electronic health records for patients and the availability of thousands of mobile phone applications for managing a wide range of health and health-care topics. Even when examining the uptake of technology internationally, it is

clear that the digital divide is shrinking between low- and high-income countries as well, with mobile phone coverage and use growing quickly worldwide. In fact, many of the lessons learned from implementing technology interventions in low- and middle-income countries are particularly informative for improving the health and health care of vulnerable patients in the United States.[2,3]

While the use of the Internet and mobile phones continues to climb, the frequency and type of technology access can differ among low-income patients, especially when considering Smartphone ownership and broadband Internet access. Unless these gaps in technology access are addressed, information tools that require personal computer or Smartphone use will continue to present challenges for socioeconomically vulnerable communities.

In addition, socioeconomically vulnerable patients often have limited health literacy,[4] limited English proficiency, or other communication challenges that serve as formidable barriers to the use of most standard mHealth services. Consequently, these patients may have difficulty accessing "off-the-shelf" mHealth solutions, even when those technologies have proved beneficial for other patient groups. A recent review of the evidence found that studies reporting on the usability of diabetes Internet and mobile phone applications rarely addressed issues of accessibility for diverse or vulnerable patients.[5] Despite these potential barriers, safety-net health systems striving to improve treatment access and quality can use mHealth successfully if careful attention is given to how those services are designed.[6]

This chapter discusses the principles that should drive the design and development of mHealth services so that they are accessible and effective in diverse populations of patients. The focus is primarily on the use of mHealth to promote more effective communication and disease management among patients with chronic health problems, such as diabetes, heart failure, or depression. These patients represent the majority of visits and uncompensated health-care costs within safety-net heath systems. Such patients often lack the resources required to manage their condition successfully, and access barriers significantly add to the difficulty of meeting the demands of their illness. Rather than focus on specific types of mHealth technology (such as web-based applications or interactive voice response systems), the chapter focuses on concepts that are relevant for most currently available technologic platforms. Each health-care system must choose the appropriate platform for delivering the health technology programs outlined below—whether it be texting, automated telephone calls, clinic-based multimedia supports, or other web-based programs. Matching existing technologies to the skills and capacity of both the patient population and current care processes within the health-care setting will best utilize mHealth solutions to address gaps in care.

THE FUNCTIONS OF INTERACTIVE HEALTH TECHNOLOGIES IN CHRONIC ILLNESS CARE

When implemented effectively, mHealth can be helpful in redressing the difficulties faced by safety-net health-care systems and the patients they serve. Financial access barriers, geographic distance, language barriers, long waiting times, and restrictive work schedules all conspire to make typical face-to-face communication within outpatient settings especially difficult for socioeconomically vulnerable patients.[7] In general, mHealth technologies can assist patients to get support managing their chronic conditions either through direct communication with providers or access to relevant health and self-management information. Many chronically ill patients may need weekly or even daily support for their self-care; however, such demands strain even the most effective care management systems and are impossible to meet by most safety-net providers. Many patients within safety-net health-care systems are complex and often have multiple chronic comorbidities which make the prioritization of discussion topics with their provider even more challenging.[8,9] Despite the obvious importance of clinician–patient communication, health-care providers often are unaware of patients' self-management goals[10] or the financial pressures that patients struggle with because of their treatment,[11,12] issues that may be clarified and communicated to the provider through mHealth programs.

Many mHealth-based disease management interventions (particularly those developed in the early 1990s) attempted to address multiple self-management problems simultaneously. Earlier enthusiasts of these new technologies seemed to operate based on the expectation that (because they were so novel and exciting) technology-based interventions per se would have a therapeutic benefit, and therefore careful consideration of intervention goals was less important. However, like all clinical services, mHealth-based services are most effective when they are designed with specific, targeted goals in mind (Box 17-1).

Box 17-1. mHealth Goals for Chronically Ill Patients

- Assisting patients with administrative tasks (e.g., remembering when follow-up visits are scheduled).
- Ongoing patient monitoring and surveillance to identify health and behavioral problems.
- Delivering patient education or other information to assist in disease self-management, including personalized feedback on self-care behaviors.
- Facilitating informal support (e.g., peer support) for coping with illness.

USING mHEALTH TECHNOLOGIES TO SUPPORT ADMINISTRATIVE PROCESSES OF CARE

> Ms. Sepulveda, a 53-year-old Spanish-speaking woman, has diabetes and hypertension with persistently elevated hemoglobin A_{1c} and blood pressure. Her prescription for a glucometer has been denied at her usual neighborhood pharmacy because of changes in her insurance coverage. With her son's help, she recently registered for access to an online patient portal to be able to view her medical record information on a secure website. Through the portal, she and her son are able to email her primary care team to inquire about the glucometer. The medical assistant who responds to the email provides information about obtaining diabetes supplies via the hospital pharmacy and checks in with Ms. Sepulveda about her remaining refills for her other diabetes medications.

Chronically ill patients face a daunting task when managing their health problems: handling numerous medications, coordinating repeated visits to different clinicians, and navigating the continually changing requirements for insurance or benefits. Even those with insurance can be financially strained by the costs of treatments and medications. Studies indicate that chronically ill patients have difficulty meeting these administrative challenges, particularly if they have little education or limited English proficiency. Patients often miss scheduled appointments, and no-show rates are often highest among individuals with the greatest need for clinical care.[13] More than one-third of diabetes patients with either no health insurance or Medicaid coverage reported forgoing prescription drug use in the prior year because of cost concerns, despite the fact that those patients were almost universally eligible for first-dollar medication coverage through state and regional financial assistance programs.[12]

mHealth programs can assist patients managing the complexity of their health service use as well as their self-care. Automated reminder calls delivered via a computerized "interactive voice response" (IVR) telephone system to patients undergoing medication treatment for tuberculosis increased visit attendance rates relative to controls.[14] Even though patients were not aware that IVR reminders would be coming to their homes, the calls were effective for patients with a variety of primary languages, including Mandarin, Vietnamese, Tagalog, and Spanish. Other studies have found that automated reminders can increase attendance rates for routine vaccinations[15] and can assist patients in taking their medications as prescribed.[16] Importantly, "low-tech" alternatives to automated telephone calls (such as reminder letters) also improve attendance rates,[17] but IVR reminders are cost-effective when compared with these more labor-intensive alternatives. High patient engagement with IVR technologies has also been documented in low- and middle-income countries, suggesting that this approach for chronic disease self-management support is adaptable for diverse patient populations.[2,3,18] The technology used to deliver IVR reminders is relatively simple and inexpensive (especially with the increased ability to employ very low-cost voice over IP (VoIP) technology to deliver the calls),[19] and the research in this area is sufficiently definitive that safety-net providers should consider incorporating such reminders into usual outpatient care.

Other forms of mHealth, such as text messaging to cell phones, may be effective in assisting vulnerable patients with the administrative functions of their disease management. Recent systematic reviews have found that texting can significantly improve appointment adherence and self-efficacy for chronic disease self-management, but there is far less evidence that such interventions can improve clinical outcomes such as glycemic or blood pressure control or weight loss.[20,21] In addition, texting programs have been shown to improve smoking cessation rates.[22] However, there have been fewer studies of texting conducted in socioeconomically vulnerable patient populations. Among patients in one safety-net system in Chicago, patients reported high satisfaction rates with texting programs for medication reminders, as well as self-reported improvements in medication adherence and overall confidence in diabetes self-management.[23]

Finally, the introduction of personal electronic health records, or patient portals, may assist patients in managing the administrative tasks associated with their chronic illness care.[24] These systems can provide patients with access to a variety of functions associated with their care: from secure email with providers and staff; viewing visit summaries, lab results, and medical histories; and online appointment scheduling and refill requests. Studies in large delivery systems such as Kaiser, Group Health, and Cleveland Clinic have reported that patients with access to portals are more likely to have improved diabetes control,[25-27] suggesting that the convenience of completing several administrative tasks may be linked to better outcomes. Patient access portals or secure emailing with providers has been more limited in safety-net systems, but there is high interest in electronic communication with health-care providers among this patient population.[28,29] The introduction of portals into safety-net settings in the next few years with US health reform will provide a wealth of opportunities for evaluating their potential.[30-32]

USING mHEALTH TECHNOLOGIES FOR ONGOING PATIENT MONITORING

> Mr. Yu, a 65-year-old Cantonese-speaking man with diabetes, is a participant in a diabetes program that uses an automated telephone outreach system. His response during an IVR monitoring call triggers a nurse callback about a foot problem, and he describes blisters on his right foot. He had recently increased his walking in shoes that no longer fit well.

> Mr. Yu had continued to walk despite the discomfort because "his doctor told him how important walking was for controlling diabetes." The nurse scheduled Mr. Yu to see the podiatrist to reassess shoe fit, and he was fully evaluated and given new shoes within 3 weeks.

Most patient monitoring occurs as reactive care during relatively infrequent face-to-face outpatient visits. Few health systems have the information systems needed to trigger a proactive and comprehensive assessment when patients seek care through different entry points (e.g., an emergency department), and many patients have difficulty keeping scheduled office visits.[33] Consequently, chronic disease treatment plans often reflect patients' historical problems more than their current needs, opportunities to prevent health crises are missed, and educational efforts lack the timeliness needed to be effective.

mHealth can assist clinicians in gathering up-to-date information about patients' health status and behavioral needs. For example, low-income patients with diabetes in the United States and abroad can and will complete brief IVR assessments of their glucose self-monitoring values and self-management behaviors.[34,35] Engagement is also high across a variety of health-care conditions, such as programs for heart failure, cancer, diabetes, and depression. These applications appear to be especially useful for patients with limited English proficiency.[36,37] IVR data are often reliable even when reported by individuals with psychiatric disorders.[38] Such assessments can accurately triage patients into groups with high-, medium-, and low-risk for adverse outcomes.

A rapidly growing area of technology development has been the design and testing of remote monitoring applications that can track patients' clinical data without relying on patients' self-reports. A recent randomized trial of veterans with back pain found that pedometers that uploaded physical activity to a website with personalized walking goals, feedback, motivational support, and social support resulted in greater decreases in pain-related disability.[39] Incorporating external device information from glucometers and blood pressure cuffs uploaded into mobile phone applications or websites can be particularly appealing if passive data capture provides both more accurate and larger amounts of data to understand a more complete picture of self-management. A randomized controlled trial of telemedicine with remote monitoring of blood pressure and blood glucose among low-income Medicare patients in New York found significant improvements in A_{1c}, blood pressure, and low-density lipoprotein control.[40] Similarly, patients with hypertension receiving IVR automated telephone self-management support with home blood pressure monitoring in Honduras and Mexico also showed improved blood pressure control, reduced medication nonadherence, better overall health status, and higher satisfaction with care.[41]

Careful consideration must be given to the ways in which health systems respond to mHealth-reported information. While the effectiveness of such systems has been documented, there are a range of issues related to implementation into an existing clinical setting, such as willingness of staff and providers to use the technology and new data sources.[42] Clinic-based "case finding" or screening with feedback to providers can have little impact on patient outcomes,[43,44] often because providers have limited ability to change practice patterns or because treatment changes are not tightly linked with health outcomes. Providers who are pressed for time or treat patients with multiple urgent complaints often lack the resources required to follow up effectively on serious, but chronic patient needs (e.g., dysthymia, functional limitations, or self-management problems). mHealth-based patient monitoring with limited clinical specificity may generate unnecessary outpatient visits, straining scarce resources in public clinics, and indirectly denying access to other patients with acute health concerns. Given the state of the science in mHealth patient monitoring, safety-net providers should carefully consider the frequency and content of mHealth assessments, and the implications of both erroneously identifying patients as having serious health problems versus missing problems because of "false-negative" reports.

USING mHEALTH TECHNOLOGIES FOR PATIENT EDUCATION AND SELF-MANAGEMENT SUPPORT

> Mrs. Miller is a 48-year-old single mom who rarely attends her appointments. She has never followed through with referrals for diabetes education. As a participant in a program that uses an automated texting system she reports that she is drinking cranberry juice and sodas daily. She is not aware that this makes her diabetes control more difficult. After receiving tailored health education messages from the system, and a reinforcing phone discussion with the nurse about the importance of trying to avoid sugary foods and drinks, Mrs. Miller makes a behavioral action plan and begins diluting her juice with water, and drinking diet soda. Her diabetes control improves.

Patients with chronic illnesses require enormous amounts of health information that change with the disease course. Unfortunately, providers infrequently engage in the types of communication behaviors that are associated with greater patient retention and understanding,[45] and many are unaware of their patients' self-management goals.[10] When patients face language barriers or health literacy deficits, many lack even rudimentary information about their disease or its self-care.[46]

mHealth can provide patients with the information they need at a time when they are best able to assimilate it. Unlike written patient education material, mHealth resources such as those provided via the web can be multimodal (i.e., including graphics, video, and audio) and provide information at a pace that is comfortable for users.[47] Importantly, the information provided by mHealth can be tailored to patients' unique sociodemographic, clinical, and psychological characteristics; and studies show that such tailoring can be important in prompting behavior changes.[48] For example, patients with diabetes are interested in receiving health education via mHealth,[49] and non-English speakers treated in public clinics may be especially interested in accessing IVR health education with practical information or inspiring messages about self-management, such as how to cope with medication side-effects and how to cook healthy meals.[50] Patients with diabetes from a safety-net clinic who received weekly IVR messages over a 9-month period also reported significant improvement in their self-management behaviors and functional status, as well as greater improvements in these outcomes when compared with patients who attended monthly group medical visits and usual care.[51]

Most patients remember only a small proportion of the educational messages provided during typical outpatient encounters.[52] Given that many patients spend a significant amount of time waiting to be seen by clinicians, safety-net health systems should consider making interactive kiosks available within outpatient settings,[53] which can provide self-guided educational content about a wide variety of health topics through a standalone computer. Recent research has demonstrated that kiosks can be a viable education tool in safety-net clinics, pharmacies, and community centers. One study reported as many as 600 uses per month, with the most viewed modules for recipes and meal planning.[54] Another similar study found that kiosks in community settings with personalized information about self-care management could improve self-reported diet and physical activity among Latino patients.[55]

Additional research has explored the use of embodied conversational agents or avatars to deliver health education and promotion content, delivered either through clinic kiosks or on tablets that can also be accessed at home. This conversational agent technology may better capture aspects of in-person communication by using dynamic verbal and nonverbal conversational behaviors, and it has been shown to be an effective way to communicate with patients with limited health literacy.[56] It has been shown that this approach could also increase physical activity among older adults in the short term.[57]

Models for computer-assisted self-management education are available,[58] and research shows that they can assist patients in identifying self-management goals and barriers, and ultimately improving their self-care. In the context of busy primary care practices,[59] such services can address patients' need for self-management education without adding tasks to the schedules of primary care providers.

USING mHEALTH TECHNOLOGIES TO FACILITATE INFORMAL PEER SUPPORT

Safety-net health systems are often poorly positioned to address patients' need for assistance in coping emotionally with their illness, and mental health insurance benefits are typically inadequate to meet patients' need for counseling. Chronic illness can present an enormous emotional drain on patients. Depression is common among patients with diseases such as diabetes and heart failure,[60,61] and patients with comorbid psychiatric problems often have worse outcomes[62,63] and increased rates of service use. Many socioeconomically vulnerable patients lack effective social support, and low social support is a risk factor for poor self-care and increased morbidity and mortality.[64,65]

Patients who provide peer support to others with the same health condition may address some of these challenges. Patients who provide support to others may achieve health benefits themselves; for example, less depression,[66] heightened self-esteem and self-efficacy,[67] improved quality of life (even after adjusting for potential confounders),[68] improved health behaviors,[69] decreased mortality risk,[70,71] and improved health outcomes and function.[72,73] Peer support can be especially effective in reducing problematic health behaviors[74,75] and mental health symptoms.[76] Most models of providing chronic disease peer support require patients to attend frequent face-to-face visits; most patients who might benefit do not attend, and those who do often drop out after a few encounters. Unfortunately, studies evaluating mHealth-facilitated opportunities for peer support have shown mixed results.[77,78] For example, online social networks in Korea were found to increase social support among participants, and this in turn increased patient empowerment and active communication with providers.[79] A longitudinal study of a peer-led online pain self-management program in England found decreased symptoms and improved health behaviors and self-efficacy.[80] Existing public social networks for patients with diabetes, such as those hosted by professional associations, have also been evaluated, with a high amount of variability in the quality of the information provided and the protection of the privacy of participants.[81,82] Importantly, mHealth-facilitated informal support services are feasible; however, there is currently little evidence for or against these interventions' impact on patients' self-management or health outcomes.

- Poorly supported mHealth programs can lead to increased resource use devoted to clinically insignificant problems.
- mHealth services are less effective when they are overly complicated and therefore address multiple issues only superficially. Programs that include a smaller number of well-designed functions, such as reminders, monitoring, and the provision of self-management education, may be more effective.
- Not all patients benefit from mHealth interventions. Some do not need additional support and/or training; others such as those with unstable residence or cognitive impairment may not be successfully targeted by generic programs. To be effective for marginalized patients, such as the homeless or severely mentally ill, mHealth requires special adaptations and personalized professional interpersonal support.
- Developing an mHealth program without active usability testing by end users (both patients and providers) is unlikely to work.
- mHealth systems that do not involve interactions with clinicians and are not integrated into primary care have limited benefit and actually may lead to confusion.
- mHealth programs are an adjunct, not a replacement or alternative, to personalized care.

THE CHARACTERISTICS OF PATIENTS WHO CAN BENEFIT FROM mHEALTH TECHNOLOGIES

Patients with a variety of sociodemographic and clinical characteristics, including those with limited functional health literacy or English proficiency,[49] can and will use mHealth as part of their usual outpatient care. In fact, among patients with poorly controlled diabetes, those with limited functional health literacy or English proficiency were more likely than those with adequate health literacy and English speakers to engage with the system (Figure 17-1). Consequently, if designed with the end-users in mind, IVR and other mHealth systems may have the greatest uptake among patients with communication barriers who often are highly motivated to engage with systems that increase their access to care. Depending on communication channel through which the mHealth program is delivered (e.g., automated phone calls vs. texting), age and technical skills may also influence patient engagement and use.[83] In future work, offering the same content through multiple channels may increase the accessibility of the mHealth program, and training and support for certain patient subgroups may increase program uptake and ongoing engagement.

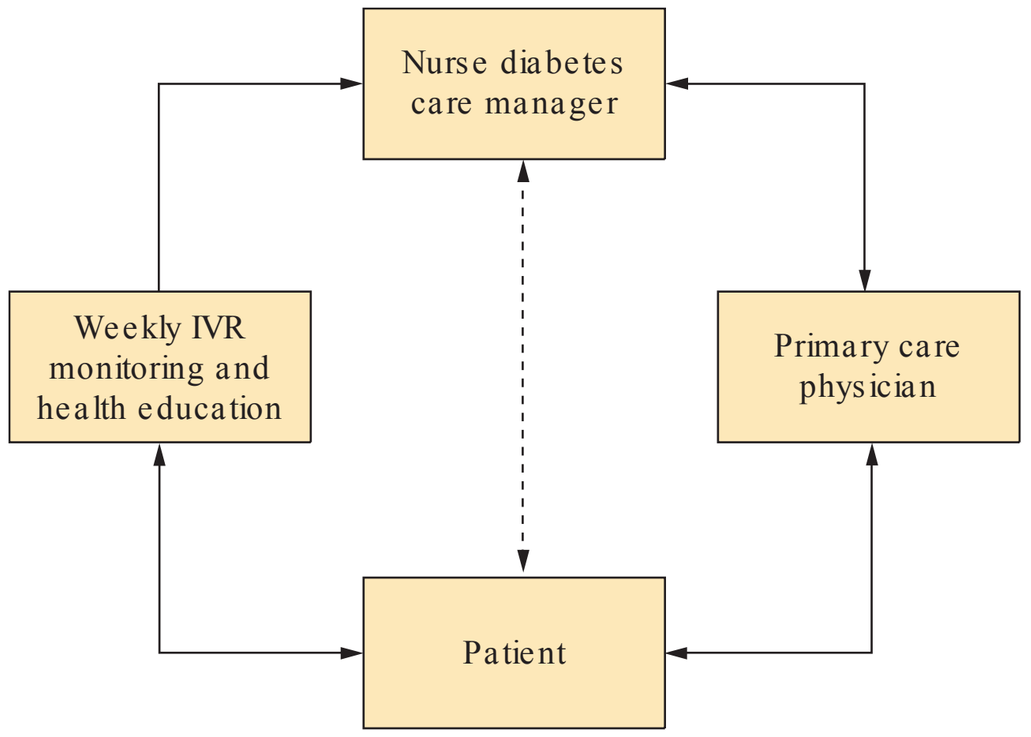


Figure 17-1. The Interactive Voice Response (IVR) System of the IDEALL Project. With extensive input from patients, the authors designed an IVR system sensitive to the literacy and language requirements of the target population. Each week, patients receive a rotating set of questions about diabetes self-care, psychosocial aspects of diabetes care, as well as receipt of preventive services. Patients who answer out of range on an item (based on predetermined thresholds) receive an immediate automated health education message in the form of a narrative to encourage them to reflect on their self-care behavior and consider setting goals and developing an action plan around self-care. Patients who answer out of range also receive a call back from a bilingual nurse care manager to encourage them to set goals and develop an action plan to improve their overall health. The nurse care manager is trained to perform motivational interviewing, assess and overcome barriers to successful diabetes care and health communication, and suggest changes in medical management. Guided by a clinical protocol, the care manager communicates with patients' primary care physicians to implement such changes. The IDEALL Project system is designed in such a way as to promote the efficiency of the nurse care manager by having her only perform those outreach phone calls to patients who, by virtue of their responses to the system, report a need for further support. The IDEALL system requires about 10 minutes to complete per week, and runs for 39 weeks (9 months).

The potential benefits of mHealth technologies are unlikely to be equally distributed across patients. Many patients, including some treated in safety-net health systems, already have the resources they need to manage their illness effectively. As a result, they may receive little additional benefit from the types of support (e.g., reminders, ongoing monitoring, patient education, and informal support) that are possible through mHealth.[84,85] At the opposite extreme, some patients treated by safety-net

providers lack the basic necessities that would be essential to take advantage of the support available through mHealth. In particular, patients with serious psychiatric disorders, unstable residences, or inconsistent telephone access may not benefit from the types of services even the most creative mHealth can provide.

Safety-net providers should carefully consider which patients could benefit from mHealth-based self-management supports. Often, patients with the poorest health status (e.g., diabetes patients with the worst glycemic control or heart failure patients with repeated acute exacerbations) are targeted for these additional services; however, these may not be the patients who can benefit the most. Rather mHealth may be of greatest benefit to patients who fall between the two extremes of adequate self-management support and intractable social or psychiatric need, that is, the large number of patients who simply need additional reminders, monitoring, self-management information, and other services that they cannot access through usual outpatient sources of care.

LINKING INTERACTIVE HEALTH TECHNOLOGIES WITH USUAL PROCESSES OF CARE

Studies suggest that the outcomes of mHealth services are proportional to the extent that they support "live" clinician resources and are integrated with usual processes of outpatient care (Figure 17-2). When mHealth programs are not linked to clinical responses, improvement in knowledge and perceived social support may occur, but only slight benefit in the more important realms of self-efficacy, health behavior, or health outcomes can be demonstrated.[86] In addition, mHealth programs that are closely linked with patients' usual outpatient services are used more consistently over time and may improve important outcomes such as cholesterol levels, symptom burden, and rates of preventable hospitalizations. Furthermore, having a centralized, guideline-driven system for mHealth that reacts to concerning patient responses—for example, through a nurse care manager—may ensure more consistent and effective treatment plans. Linkages to existing processes are likely important even beyond the clinic level: evidence from successful innovative diabetes programs internationally found that collaboration between academic centers, hospitals, as well as community resources and businesses was a key factor to success.[87]

mHealth services most closely integrated with patients' outpatient primary care can improve behavioral and health outcomes. For example, rigorous randomized trials have investigated clinic-based behavioral assessments delivered via a multimedia kiosk in order to identify barriers to self-management and structure behavioral interactions between patients and their clinicians.[58,85] Such systems have shown consistent, lasting impacts on difficult-to-change behaviors (e.g., diet) as well as physiologic outcomes (e.g., cholesterol levels). In addition, several randomized trials have demonstrated that IVR assessment with rapid follow-up by a telephone nurse care manager can improve outcomes for patients with diabetes or hypertension[84,88-90,91] or improve survival among patients with advanced congestive heart failure.[77]

"STANDALONE" INTERACTIVE HEALTH TECHNOLOGY INTERVENTIONS

In general, interventions designed to operate as standalone services (i.e., interventions that are completely automated, with no follow-up by clinicians) may be seen by patients as superfluous and be used with decreasing frequency over time.[92] For example, Pinto and colleagues developed a call-in IVR program to assist patients with increasing their physical activity levels.[89] Although the recorded messages were tailored and based on sound health behavior change theory, the investigators found that as many as one in four study participants never called the toll-free number to receive behavior-change messages, and fewer than half were using the system after 3 months. Not surprisingly, the intervention had no significant impact on patients' behavior. Incomplete linkages to clinicians or provider care teams may produce modest health improvements. In randomized trials in which patients were connected to an "e-counselor" for weight management (not directly connected to existing primary care teams), investigators found some improvements in weight loss and engagement with the web-based system.[93,94] However, all patients regardless of intervention arm significantly decreased their log-ins to the website

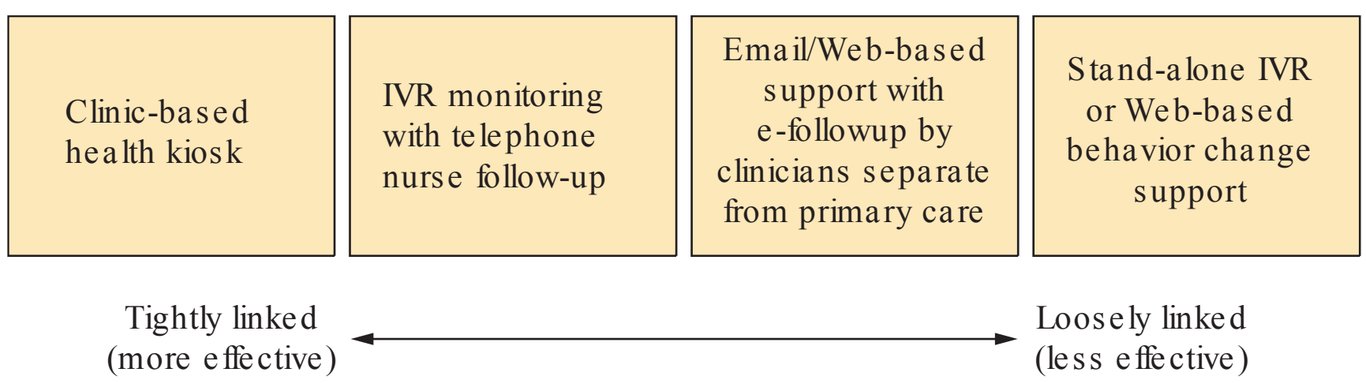


Figure 17-2. Relationship between mHealth linkage to patients' usual clinical care and evidence of intervention effectiveness.

over time—highlighting the need for even greater linkages to ongoing care to maximize patient engagement.

HOW SHOULD SAFETY-NET PROVIDERS DELIVER INTERACTIVE HEALTH TECHNOLOGY SERVICES?

Numerous private companies produce generic versions of the hardware and software required for implementing mHealth services within a safety-net health system. Other companies are clinical service providers and offer mHealth-supported care management services by charging health systems on a per-patient-per-month basis or other capitated model. The choice of whether to provide mHealth services "in-house" or through a contracted service agency is important, and both options have their advantages.

IN-HOUSE mHEALTH DELIVERY

One advantage of in-house mHealth delivery is that the health-care organization can have more control over the intervention process and content. For example, in-house mHealth services can provide greater opportunity to modify the patient messages, integrate systems with electronic health records, or design and change clinician reports. One issue to explore when considering outsourced mHealth supports is that making changes in patients' communication protocol could be more difficult and costly because of distance barriers and the company's financial incentives.

A disadvantage of in-house mHealth service development and delivery is that the responsibility for managing the technical aspects of the system falls on the health-care organization. Most mHealth systems require the use of specialized programming languages and equipment; health systems need to consider whether they have the resources to fund this infrastructure over time. Although it is not clear whether in-house or subcontracted mHealth is less costly in the long term, equipment purchase for in-house mHealth may represent a significant initial investment, whereas subcontracted costs can be more constant and predictable.

SUBCONTRACTED mHEALTH SERVICES

An important issue to address when using subcontracted mHealth services is that these services may complicate care coordination, especially if the vendor includes its own health educators and other health personnel who provide follow-up when a patient problem is identified. Those clinicians often do not have access to patients' complete medical records and could make inappropriate changes to treatment plans if clear lines of communication are not established. Without clear protocols for information exchange, even appropriate advice or medication adjustments by outside staff may not be communicated to patients' primary care team or documented in patients' charts. Because many patients receive care from multiple providers, clear and consistent lines of communication between mHealth services and others involved in patients' care are critical so that patients do not become confused as to where they should turn for help when they have a clinical or technical problem using the mHealth system.

EVALUATING INTERACTIVE HEALTH TECHNOLOGIES

mHealth can improve the disease management and health outcomes for patients treated by safety-net providers, assuming careful thought is given to the intervention's functioning, the patients, and clinicians it is designed to serve, and how it relates to other aspects of patients' care. Evaluations of new mHealth services should reflect the intervention's goals. For example, an intervention designed to increase rates of ophthalmologic examinations among patients with diabetes may not save an organization's money in the short term, and decision makers should be clear about desired evaluation criteria up front. As described in previous sections, mHealth interventions can play multiple roles in chronic illness care; it may be difficult to implement an intervention that addresses both the goal of cost containment and of increasing use of guideline-recommended services simultaneously. Priorities should be set to select the optimal role of the system in the context of other available services.

If the mHealth solution was not designed or tested with input from vulnerable patients in the context of their everyday life, then it is more likely to be underutilized or ineffective. User-centered design principles can be particularly useful in creating mHealth technologies for vulnerable patients, such as observational "think-aloud" interviews to systematically document when patients experience barriers or questions when interacting with early versions of the system.[5,95] However, it is often the case that health-care systems serving vulnerable patients attempt to adapt an existing technology that was originally implemented with a different patient population. Taking the time to pilot an mHealth system with a diverse patient population and adapt it in an iterative manner can greatly improve the functionality and accessibility of the technology as well as the subsequent implementation of the program within real-world practices.

Once broader implementation is underway, the traditional gold standard for determining the potential benefits of novel services such as mHealth has been evaluation within the context of a tightly controlled randomized trial. However, many services that have proved efficacious in a research context have shown disappointing results

in more "real-world" settings or have not been translated into services that can benefit patients in typical outpatient practices. Consequently, policy makers and clinicians have begun to conceptualize evaluation more broadly than randomized trials. Pragmatic trials have been introduced to aid with the translation of findings into real-world practice—that is determining how programs work under usual conditions present in health-care settings, rather than ideal conditions within a more tightly controlled clinical trial—which is particularly relevant for understanding how to adapt mHealth programs for safety-net settings.[96]

The RE-AIM (Reach, Efficacy, Adoption, Implementation, and Maintenance) framework is one tool for evaluating mHealth implementation in diverse practice settings. This framework suggests that these services (particularly clinic-based multimedia educational systems and IVR) may be useful despite only modest impacts on patient outcomes, because of their low marginal cost, ease of use, and ready availability to patients facing access barriers.[97] Safety-net providers may find that mHealth can benefit their patients by using perspectives such as that provided by RE-AIM. This framework is particularly important when adapting technology solutions from other settings to safety-net systems, as both the initial adoption and sustained use of the mHealth solution may look different depending on the patient and system characteristics.

CONCLUSION

New mHealth services are constantly being developed in parallel with new technology devices that expand communication for all patient populations. The introduction of health information technology in safety-net health-care settings is also expanding quickly because of health reform and the widespread introduction of patient portal systems. As traditional health-care resources evolve, mHealth may be able to fill the gaps that arise in care within safety-net health systems that result from the imbalance between the needs of patient populations and the fixed capacity/supply of providers. With careful attention to how mHealth services address long-standing clinical challenges, these tools may alleviate some of the stresses on safety-net clinicians, especially if technology can provide the self-management support for patients between outpatient visits that is crucial but often impossible to deliver through traditional practice models.

- mHealth can serve four goals in chronic illness care:
  —Assisting patients with administrative tasks such as remembering to attend upcoming appointments.
  —Providing ongoing monitoring of patients' symptoms, physiologic values, or health behaviors.
  —Delivering patient education and supporting self-management by providing personalized health behavior feedback.
  —Facilitating communication with other patients or social network members that can provide informal support.
- Before implementing a new mHealth program, it is important to carefully consider the program's goals and target users.
- Interactive voice response (IVR) systems are simple and inexpensive tools, with substantial evidence for effectiveness and should be considered for use by safety-net providers.
- If carefully designed with input from end users, mHealth technologies have great potential to improve vulnerable patients' access to care, health information, and social support.
- Patients can provide reliable clinical information via mHealth between outpatient encounters.
- Interactive educational kiosks used in outpatient settings can assist patients in self-management and behavior change efforts.
- mHealth-facilitated informal (peer) support services are feasible, but their impact on patients' self-management or health outcomes has not been demonstrated.
- mHealth is most effective when closely linked with usual outpatient care.
- Text messaging interventions can be effective for improving health behaviors such as appointment attendance, medication reminders, and smoking cessation.
- While smartphone applications hold great promise, no studies have shown that they can improve outcomes in vulnerable populations; access to smartphones with reliable data plans is far from universal in low-income communities.

mHealth: Assessing Your Practice Setting and Clinical Challenges

Could an mHealth technology help your patients achieve self-management goals and avoid complications of their chronic disease?

- Define a problem that you would like to address.
- What traditional methods have you employed to address the problem?
- Why have these approaches failed or only partially succeeded?
- What types of mHealth technologies do you think might help address the problem?
- What are clinician attitudes toward integrating mHealth applications?

- What are the characteristics of patients and which adaptations might your mHealth need to have the greatest reach and effectiveness?

Review "off-the-shelf" programs

- Will they work for your setting and your patients? Have they been tested for usability in a similar patient population?
- Can you adapt them to suit your needs?
- Do they allow for integration with clinic personnel and workflow?
- What would be the purchase cost overall and per patient served? What would be the impact on the costs of other services your organization provides (e.g., follow-up calls to address problems identified via the mHealth service)?
- Do you have resources and staff to support the mHealth or develop and implement your own?

DISCUSSION QUESTIONS

1. mHealth services (e.g., regular IVR assessment calls) may identify important health or self-management problems between outpatient visits. However, such systems also may provide ambiguous clinical data that require additional follow-up by clinicians. Given that most safety-net health systems are already burdened with pressing patient care problems, what are the benefits and costs of "trolling" for additional problems via mHealth? For what types of patients and health problems may mHealth monitoring be most useful?
2. Given the widespread implementation of online patient portals, what do you think are the greatest challenges for use among (1) vulnerable patients and (2) providers in safety-net systems? How do you think the initial challenges with adoption will differ from longer term engagement/use?
3. Should public health systems develop web- or texting-based educational supports for their patients, even though not all patients could use them? How should clinicians and administrators assess such services, so that scarce resources are used effectively without investing excessive time and money in evaluating intervention effects?
4. Clinicians need accurate and timely information to make decisions, but mHealth can add additional data (e.g., guidelines, clinician reminders, patient functional status information) to the process of care. How much information is too much? How should clinicians and health systems decide what mHealth information is helpful in patient care and what is simply a distraction?
5. Should safety-net health systems develop the infrastructure for delivering mHealth services "in-house" or contract such services with an outside vendor?

RESOURCES

For information on health information technology in the United States, see http://www.rwjf.org/content/dam/farm/reports/reports/2013/rwjf406758

For information on evaluating mHealth within the RE-AIM framework, see http://www.re-aim.hnfe.vt.edu/

For information regarding the IDEALL Project at San Francisco General Hospital, see http://www.commonwealthfund.org/publications/tools/2004/jun/better-diabetes-care-for-patients-with-low-health-literacy

For information on the use of telephone care in chronic disease management, see http://www.chcf.org/publications/2005/06/using-telephone-support-to-manage-chronic-disease

For more information on patient portals and Meaningful Use financial incentives, see http://www.healthit.gov/providers-professionals/faqs/what-patient-portal

http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Meaningful_Use.html

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Chapter 18

Applying Principles and Practice of Quality Improvement for Better Care of the Underserved

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Objectives

- Define quality improvement (QI).
- Define goals for applying QI to reduce health-care inequities.
- Describe how QI can affect health-care inequities
- Review the importance of collecting data on race, ethnicity, language, and social and behavioral risk factors.
- Review the importance of patient safety for vulnerable patients.
- Describe the "Triple Aim" QI framework.
- Describe the eight steps of a QI initiative.

Olivia has worked for 3 months at a community health center that serves a vulnerable patient population. The staff is wonderful, with many dedicated people, but some are worn down by chronic staffing shortages and overwhelming patient needs. The patients are very poor with many psychosocial stressors. Some have no telephone or are homeless; others cannot afford bus fare to the clinic; about at third speak little or no English. A small yet significant number of patients use illicit drugs. Olivia has been given 10% "QI time" in her job description to help the clinic tackle long-standing quality of care issues and to start making some operational and clinical improvement. While finding the task somewhat daunting, she is excited to dive in. However, she is not sure how to begin.

INTRODUCTION

Even the most dedicated and idealistic practitioners can be daunted in their quest to care for complicated patients in limited resource settings. Health-care delivery systems can support the individual practitioner in that quest. Those systems that focus on continually improving patient health (outcomes) define improved care (performance) as requiring the constant, combined efforts of everyone in the system. System-based approaches to improving patient outcomes and care can follow formal methods of analysis and strategies for progress.

Quality Improvement (QI) is one system-based approach borrowed from other industries that has been applied to health care. The Agency for Healthcare Research and Quality defines QI as "a multidisciplinary, systems-focused, data-driven method of understanding and improving the efficiency, effectiveness, and reliability of health processes and outcomes of care."[1,2] While interest in QI has exploded in the United States over the past two decades, the extent to which those efforts have improved health care for vulnerable patients is unclear. This chapter addresses the specific challenges of quality improvement in safety-net settings with vulnerable patient populations. We present an eight-step approach to designing, implementing, and evaluating QI efforts, emphasizing

data-driven and team-based approaches, adapted from the Institute for Healthcare Improvement. We describe concrete steps that can be used to guide QI efforts, with advice about how to adapt or expand their use in safety-net settings.

QUALITY IMPROVEMENT AND VULNERABLE PATIENT POPULATIONS

Since the publication of the Institute of Medicine (IOM) report "Crossing the Quality Chasm,"[3] a report that documented the ways in which the US health-care system not only failed to deliver high quality care but actually harmed patients, the United States has experienced a surge in QI activities. QI efforts have been closely tied to efforts to improve patient safety (see "Patient Safety and Vulnerable Populations") and to decrease medical errors. While there is debate about how best to improve quality,[4,5] QI has succeeded when there is engaged leadership, adequate resources, and experience, and the processes are data-driven, stepwise approaches to improving services. Quality improvement efforts have been promoted by many organizations.

The potential for QI initiatives to decrease health disparities has long been recognized. In the report "Crossing the Quality Chasm," from the Institute of Medicine (IOM), included improving "equity" and reducing racial and ethnic disparities as one of the six critical pillars of improving health-care quality in the nation.[3]

The IOM's 2003 report, "Unequal Treatment," further focused attention on health-care disparities. However, the traditional, implicit stance of the QI movement has been that, while health-care disparities exist and should be addressed, a well-designed QI initiative will be of benefit to all patient groups. The Institute for Health Care Improvement, for example, in their 22-session QI educational series for health-care trainees, has no module that addresses the relationship of QI and health-care disparities,[6] or how to use QI to address health-care disparities. The assumption has been that overall improvement in quality of care will help patients vulnerable to health-care disparities, or that a "rising tide lifts all boats."

The Health Research and Services Administration's (HRSA) National Health-Care Disparities initiative, on the other hand, has explicitly attempted to link quality improvement efforts with a reduction in health-care disparities. Nevertheless, the vast majority of QI initiatives have had neither the explicit goal of decreasing health-care disparities nor have they assessed the interventions for their impact on health-care disparities. Failing to explicitly consider the needs of vulnerable patients and neglecting to assess the impact of QI initiatives on patient subgroups may result in actually creating health-care inequities. The QI efforts may not benefit all groups equally or could, in some cases, decrease health-care quality for some patient groups.

As the number of vulnerable patients increases, it is especially critical to realize the potential of QI efforts to reduce health-care disparities. Recognizing the major challenges to ensuring that QI efforts reduce racial, ethnic, and language disparities is vital for success.[7] Documenting disparities is never a comfortable undertaking, even when attempting to improve them. Indeed, attempting to diminish the appearance of disparities can create perverse incentives for providers to avoid serving vulnerable patients altogether. Fully engaging vulnerable patients in QI programs may also present difficulties due to language or other barriers. QI projects must also be tailored to address specific needs of vulnerable populations. Furthermore, institutions that provide care to underserved patients may not have the resources to fully implement adequate QI programs.

To assure that QI initiatives realize their promise to decrease health-care inequities, they must be designed specifically to do so. Health-care disparities should be assessed before, during, and after implementation of the initiative. Careful attention needs to be paid to avoid incentives for providers to avoid higher-risk patients. Interventions also must be fashioned to overcome barriers to implementation. For example, programs need to be applied regardless of patient language and in organizations that care for minority patients or patients with socioeconomic challenges.

PATIENT SAFETY AND VULNERABLE POPULATIONS

> Mr. P, a patient with long-standing diabetes on insulin and a major depressive disorder, had a syncopal episode while riding the bus. He was taken to the emergency department, where he was found to be hypoglycemic. He subsequently revealed to his primary care provider that he occasionally skipped meals because of lack of access to food, and was not knowledgeable about how to manage his diabetes medications when he did not eat.

Patient safety, or the prevention of harm to patients, poses particular challenges for vulnerable populations.[8] Communication challenges such as limited health literacy or limited English proficiency can make self-management of chronic diseases very difficult for patients and families. Inability to interpret medication labels correctly, for instance, can lead to poor or dangerous medication use.

Poverty impedes the management of chronic conditions in indirect ways, such as not adhering to medications due to cost,[9] or direct ways, such as lack of food access leading to hypoglycemia.[10] Moreover, economic

pressure increases the demand of caregiving, as vulnerable patients and families choose between lost wages and supervision of ill family members.

THE IMPACT OF QI ON HEALTH DISPARITIES: FOUR POSSIBLE SCENARIOS

A review of several different QI projects demonstrates some of the complexities in understanding the effect QI projects may have on health-care inequities (Figure 18-1).

SCENARIO A: IMPROVED CARE AND REDUCED DISPARITIES

In some cases, QI initiatives have improved the quality of care for all patients and closed the health-care gap for our most vulnerable patients (Figure 18-1A). One large-scale example is HRSA's Health Disparities Collaborative, where health-care disparities in cancer screening were reduced through a traditional QI approach.[11-13] Another well-known example is a CMS initiative to improve outcomes in hemodialysis patients that both improved care overall and reduced disparities in care for African-American patients.[14]

SCENARIO B: IMPROVED CARE AND DISPARITIES UNCHANGED

In other cases, the rising tide may actually lift all boats, while disparities remain constant (Figure 18-1B). In such cases, care does improve for vulnerable patients, but no more than it improves for the overall population. Examples of this include QI initiatives in the Veteran's Administration (VA) and Medicare populations, in which interventions across multiple domains of care such as diabetes and cancer screening improved process and outcome metrics for both white and African-American populations, but because improvement was not differentially greater for African Americans, the disparity remained.[15] Another example includes the study by Jha et al of the effects of pay-for-performance on poor performing hospitals, which showed consistent overall improvement but no change in health-care disparities.[16]

SCENARIO C: IMPROVED CARE FOR VULNERABLE PATIENTS

In other scenarios, a QI initiative may not improve quality of care for a population overall—but does improve care for vulnerable patients (Figure 18-1C). A large-scale initiative to improve quality of care for patients with diabetes, for example, failed to demonstrate population-wide improvement, but analysis of a subgroup population of low-literacy patients showed significant improvement.[17]

SCENARIO D: WORSEN HEALTH-CARE DISPARITIES

Another scenario is possible, however. If incentives are applied incorrectly or the intervention's impact on vulnerable groups is not continually assessed, QI interventions can worsen health-care disparities (Figure 18-1C). The reasons for this are myriad—physicians and health-care organizations may feel that they have to "cherry-pick" patients to remain competitive, or they may design or implement interventions in ways that do not reach their most vulnerable patients. When New York City instituted its coronary artery bypass report cards, for example, hospitals instituted widespread changes in patient selection for surgery to avoid high-risk patients that would worsen their score. Using methods that included racial profiling, the bypass report cards worsened outcomes for minority patients.[18]

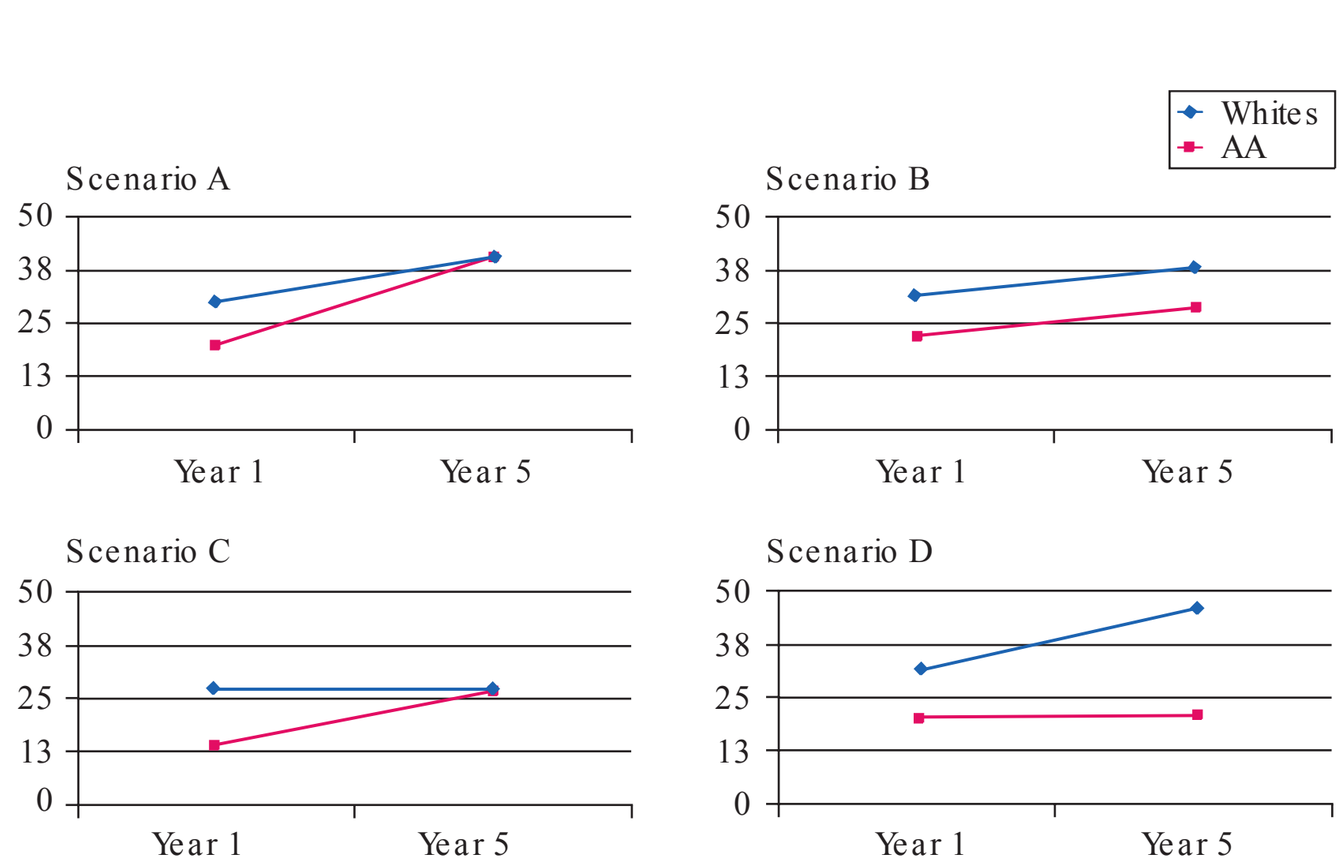


Figure 18-1. Quality improvement and health disparities: four possible scenarios.

PAY FOR PERFORMANCE AND HEALTH DISPARITIES

As the challenge of combining QI and health-care disparities reduction efforts has garnered greater attention, several approaches have emerged. These include the standardized collection of data on race, ethnicity, and English language proficiency for all patients; the creation of "equity reports" for organizations in the era of health-care reform[19]; and the careful crafting of pay-for-performance programs to encourage the reduction of health-care disparities.[20-24]

Pay for performance (P4P) refers to the increasingly common practice of offering financial incentives to physicians and other health-care providers to meet defined quality, efficiency, or other targets.[25] Although P4P remains a small portion of overall health spending and health-care provider compensation in the United States, P4P often drives quality improvement initiatives.

P4P programs may exacerbate health disparities.[20-24] Physicians and health systems caring for low-income populations care for more uninsured or publically insured patients. In turn, these systems lack resources to invest in quality improvement processes and information systems. Thus, systems that care for more advantaged populations may improve, while safety-net health systems, and the vulnerable populations they serve, are left behind. This argument is referred to as the "inverse care law," or the idea that care is least available to those who need it most.[26]

Moreover, it is clear that patients' social context affects their ability to adhere to treatment recommendations; P4P measures that encompass patient adherence to recommended screening or treatment will be influenced by patients' social conditions. Studies have demonstrated that safety-net health systems, those that disproportionately serve vulnerable populations, do not perform as well on quality reporting.[27-29] The National Quality Forum has recommended risk adjustment for socioeconomic characteristics in quality measurement and reporting, to account for social differences that impact outcomes.

In addition to risk adjustment, a further recommendation is to reward relative improvements in performance rather than an absolute performance threshold, which may benefit safety-net systems. In one study, financial incentives led to improvements in safety-net health systems, bring them on par with other health systems.[16]

PREREQUISITES FOR IMPROVING THE HEALTH OF VULNERABLE POPULATIONS

HIGH-QUALITY DATA

High-quality data defining high-risk groups and identifying disparities is a prerequisite to documenting improvements wrought by quality initiatives. Collecting race, ethnicity, and language ("REAL") data has not always occurred in clinical settings. However, several initiatives have encouraged this data collection. The National Health Plan Collaborative, for example, provided tools, coaching, and incentives to 11 major health insurance companies to improve care for vulnerable racial/ethnic groups and developed recommendations and resources for collecting REAL data.[30] The Health Research and Educational Trust (HRET) disparities similarly developed a toolkit in association with the AHA[31] (see "Resources" section). Finally, The Health Information Technology for Economic and Clinical Health (HITECH) Act mandated, with its "meaningful use" criteria, that all applicable health-care organizations routinely collect REAL data.

Although significant strides are being made to collect REAL data, this is only part of the battle. Not all vulnerable patients can be identified by REAL data, nor does REAL data assess all areas of importance to health-care disparities. Data on homelessness/marginal housing status, food insecurity, psychiatric disease, chemical dependency, and income level are also important to collect to elucidate the variability in care quality experienced by diverse patient populations. There are few national efforts to collect such data systematically and it is unclear how to collect social risk factor data in electronic health records. The IOM recommended a specific set of social and behavioral screening questions to be adopted by primary care.[32,33] Until there is a national consensus on how to best incorporate these screening questions, however, individual organizations may need to develop their own data collection efforts if they treat significant numbers of patients from high-risk groups. Of course, collecting data on REAL demographics and patients' social and behavioral factors alone does not guarantee improvement in care or health; much work is needed to analyze and act on that data. However, access to these data is the first, very necessary step toward eventual improvement.

THE IMPORTANCE OF LANGUAGE ACCESSIBLE SERVICES

In settings with immigrant patients, language-access services are a prerequisite to achieving equity in health care and in assuring the effectiveness of QI initiatives across all groups. While the importance of language-accessible services is addressed elsewhere in this book (see Chapter 31), it is worth mentioning here that the development of Culturally and Linguistically Appropriate Services in Health Care (CLAS) standards by the US Department of Health and Human Services' Office of Minority Health, as well as federal mandates to provide language assistance in healthcare centers, has helped spur significant improvement in these services and thus in the accessibility to improvement initiatives by all populations. In fact, the introduction of language-access services into health organizations is one area that has demonstrated robust improvements in clinical care in vulnerable populations.[34,35]

- Most QI projects are not designed explicitly to decrease inequities in health.
- QI projects may cause unintended harm to some patient groups.
- Measuring disparities is a prerequisite to any plan to document improvement.
- It may be uncomfortable to document disparities, potentially undermining morale and reputation.
- Failing to measure disparities can lead to unintended consequences in a QI initiative.
- Efforts to decrease disparities may paradoxically incentivize providers to avoid caring for some patients.
- Barriers to full participation for all patients are not considered when designing QI projects.
- Organizations that care for large populations of underserved patients may not have the resources to undertake robust QI projects.

ADDRESSING QUALITY IMPROVEMENT AND DISPARITIES SIMULTANEOUSLY

FRAMEWORK FOR QI: THE IHI'S TRIPLE AIM

The Institute for Healthcare Improvement (IHI) and other organizations have developed approaches to identifying and addressing quality issues in health care. IHI reframed its approach to QI, titling it the "Triple Aim,"[36] which proposes that new designs should be developed to simultaneously pursue three dimensions[37]: (1) improving the patient experience of care (including quality and satisfaction); (2) improving the health of populations; and (3) reducing the per capita cost of health care. More recently, many in the field have suggested the idea of the "Quadruple Aim," which includes staff experience and satisfaction as a fourth goal.[38] Using a multidimensional approach such as the Triple Aim allows organizations to adopt a comprehensive approach to improvement, in which attention paid to one domain does not sap needed attention from other critical areas.

> Olivia first spends some time assessing the current situation. The clinic has a good population-based registry system that allows her to understand how it performs against nationally benchmarked data (i.e., HEDIS, CGCHAPS). In addition to collecting quantitative data from the electronic system, she also solicits staff, provider, and patient input. Based on the available data and input gathered, she and her team select three issues to tackle first: high smoking rates, poor phone access to clinic staff, and high emergency department utilization rates. By creating an improvement plan that prioritizes three distinct issues, they create a natural set of balancing measures to their efforts.

Box 18-1. The Eight Steps of a QI Initiative

1. Find a process to improve.
2. Identify team and stakeholders.
3. Clarify current knowledge: What's been tried before? What are best practices for this issue?
4. Analyze current situation.
5. Set aims and measure to improve.
6. Design intervention.
7. Perform iterative cycles of improvement.
8. Communicate progress to stakeholders and team; collect input on next cycles of change.

THE EIGHT STEPS OF A QI INITIATIVE

Quality improvement provides for a stepwise approach to identifying and addressing quality issues in health care. One model, modifying IHI's rapid change cycle, describes the steps simply (Box 18-1).

Find a Process to Improve

Whether tackling an area of clinical quality, patient experience, or efficiency, the first step is to identify the process to improve. This is not as simple as it sounds. It is appealing to start with an interesting intervention and just implement it, but understanding if it is the right intervention for the identified problems is a complex issue.

With limited resources and staff bandwidth, determining which issues should be addressed first is an important consideration. There is an opportunity cost to everything—addressing one set of issues will mean that others will have to wait. In selecting which problems to tackle, it is important to get the input of key stakeholders—anyone with knowledge of and interest in the organization, community, and patient population.

When working with vulnerable patient populations, it is essential to determine which issues are most pertinent to the defined population. It may be beneficial to align efforts with ongoing, system-wide initiatives for which data is readily available, for example, joining a large diabetes collaborative within the state network. However, if other issues are more immediately relevant to a practice's population, it may be wiser to focus on these first—such as food insecurity if the organization works primarily with patients who are homeless or marginally housed. Careful analysis of the organization's data and information from key stakeholders should guide choices.

Identify Team and Stakeholders

One key to the success of any good QI project is the formation of a team to implement the project or initiative. The Agency for Healthcare Research and Quality defines a QI team as "the group of individuals within a practice charged with carrying out improvement efforts." To be effective, it is

recommended that the team include representatives from all areas of the practice that will be responsible for implementing changes brought about by the project; that a clear leader or "champion" be identified; and that the team meet regularly to review small "tests of change" for the project.[39]

Key stakeholders are different than a project team. "Stakeholder" is defined as anyone who will be affected significantly by—or who has a vested interested in—the problem being addressing or the intervention planned. QI projects may be undermined when a hidden or stakeholder is not included in the process. The emergency department practitioners, for example, who feel that opening a new pediatric urgent care service will affect the volume of their business; the medical assistants who have just had three new added responsibilities and may feel overwhelmed by being asked to screen for smoking at every patient visit. Key stakeholders may be able to contribute to the success of initiatives by acting as a helpful advisor or providing critical resources.

Clarify Current Knowledge

Reviewing what's been tried before and the best practices for a given issue is an important next step. It may involve a search of the literature for best practices or an assessment of the organization's prior efforts to improve the problem. Understanding how previous efforts have succeeded and failed is an important starting place for any new initiative. Evidence that the previous programs were successful may help leverage support for restoring them, while failed previous attempts may haunt new endeavors.

Analyze Current Situation

The fourth step in the QI process is to analyze current workflows (including sources of variability) and current root cause (RCA) of the problem being addressed. Workflow (or process) mapping can be done with computer programs, or with a simple wipe board or a flip chart with sticky notes (Figure 18-2). The most critical element in using these tools is using them with a multidisciplinary team that includes people with a wide range of experiences and responsibilities from nurses to front desk staff.

Analyzing the current situation includes getting input from patients on the problem and on proposed solutions. Ideally, patients can be part of the project team; at a minimum, it is important to seek out patient input as key stakeholders. Many organizations have a patient advisory board where QI ideas can be discussed. In addition, input can be solicited by having a few providers ask several patients for their thoughts during clinical encounters.

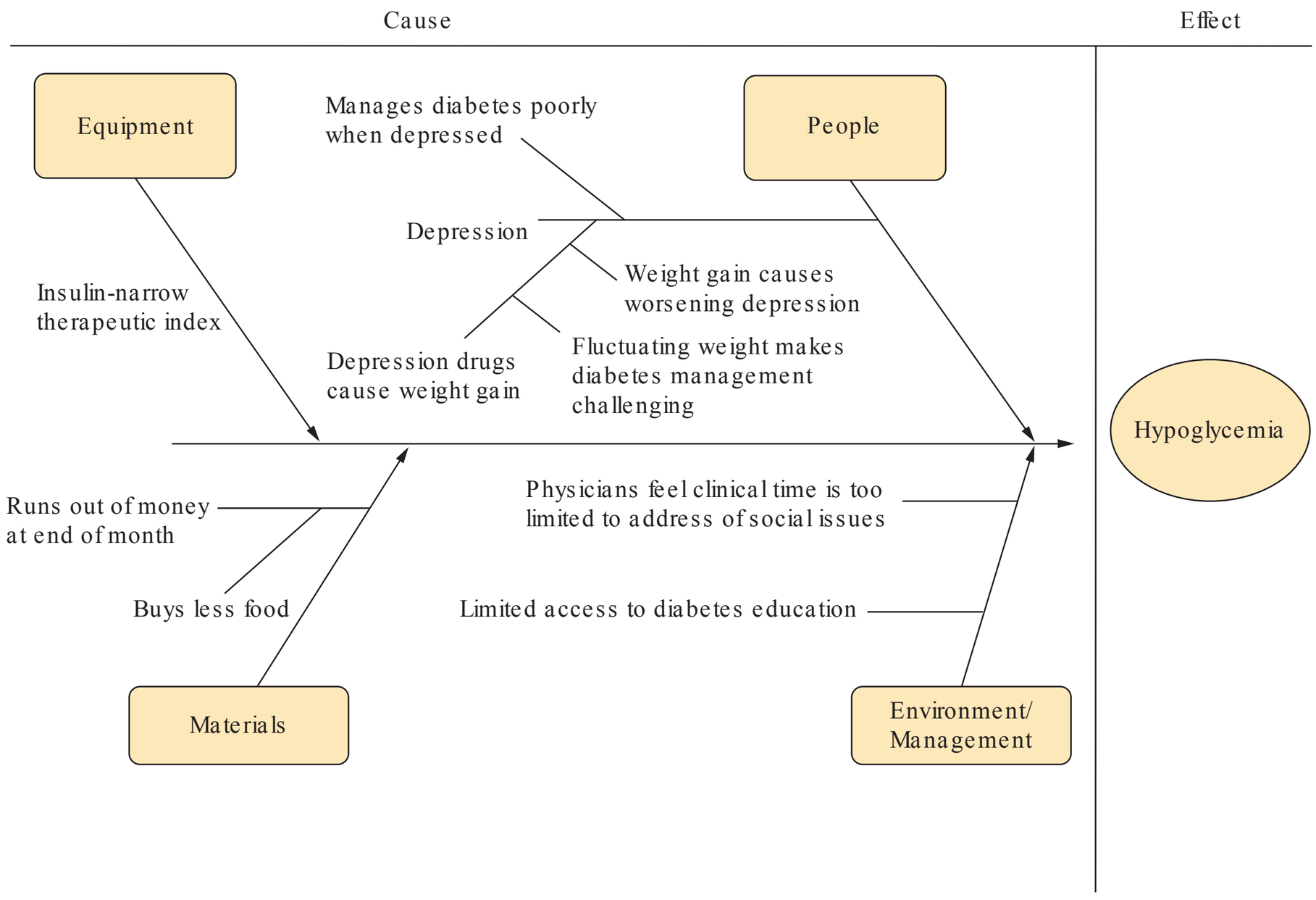


Figure 18-2. Fishbone (Ishikawa) diagram: The Ishikawa diagram seeks to identify all possible contributing causes to a problem in order to facilitate thinking of many possible solutions. The categories for the causes (equipment, process, etc.) can be modified for the particular problem under study. In this example, a case of patient hypoglycemia is analyzed. (From http://www.qualitygurus.com/qualitypedia/about/fishbone-diagram/.)

Without eliciting diverse viewpoints, critical elements of the process may be missed. As a team works through these exercises, areas of variability in task performance and unnecessary or duplicative work can be identified.

Set Aims and Select Metrics

Before launching the intervention, it is important to create goals and objectives for the project and to select a metric by which to measure project success. For multipronged, long-term interventions, long-term project planning with multiple goals and objectives may be appropriate. All interventions, regardless of size, should have at least one major objective that meets "SMART" criteria: specific, measurable, achievable, relevant, and time-bound.

Using the SMART rubric has several advantages. It clearly states the intent of the project. It requires selecting the criteria by which the project will be assessed as it progresses toward achieving the objective. It measures the effectiveness of the intervention. It establishes a timeline for the project. The SMART rubric can effectively be applied to programs addressing health-care disparities explicitly. SMART objectives can be structured to include metrics stratified by race, ethnicity, or language, for example. Most importantly, this rubric commits the QI team to a single, clearly-stated objective for the project.

QI metrics can also be defined through the structure–process–outcome framework. A structural metric is a measure of organizational characteristics (e.g., the percentage of staff who knows how to make a referral to smoking cessation counseling). A process metric is a series of actions, changes, or functions bringing about a result (e.g., the percentage of visits at which medical assistants collect smoking cessation status). An outcome metric is a change (desirable or undesirable) in individuals and populations that are linked to health care (e.g., the percentage of patients in the clinic who smoke).

In addition to having frameworks to help define metrics, it is important to set aims that are aspirational yet attainable. Objectives of limited scope or interest may undermine the impact of a project and enthusiasm for future QI projects, whereas aims that are unrealistically ambitious can be equally disheartening for the project team and stakeholders.

Olivia and her teams create the following SMART objectives for their projects:

- Within 1 year, smoking rates in the patient population will decline from 22% to 15%; and smoking rates in African-Americans and Asian men will decline by 10% (from 27% to 17% and from 30% to 20%, respectively)
- Within 6 months, the percentage of patients who rank their satisfaction with the clinic's phone access positively will improve from 50% to 65%.
- Within 18 months, emergency department visits for clinic patients for ambulatory-sensitive conditions will decline from 27 a month to 15 a month.

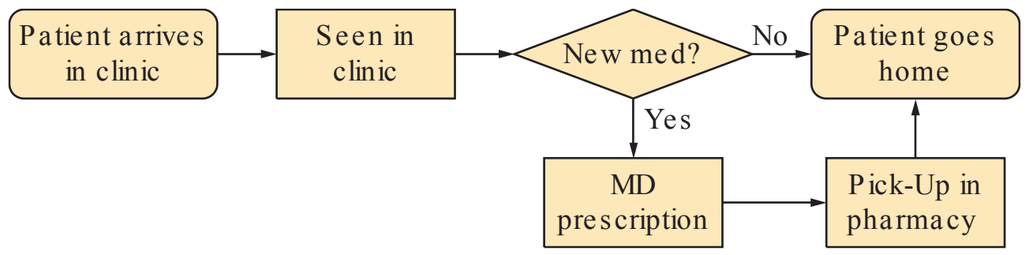


Figure 18-3. **Process mapping:** Process mapping creates a visual diagram of a current workflow (or "process.") As an exercise for a multidisciplinary group, process mapping can help identify areas of uncertainty, variability, and duplicative work in current workflows and pinpoint areas for improvement. **Above:** simplified version of a process map. (Figure courtesy of Will Huen. For more information see Agency for Healthcare Research and Quality website at https://cahps.ahrq.gov/quality-improvement/improvement-guide/analysis-of-results/Quantitative-Analyses/Performance-Problems_Tools/Process-Mapping.html)

Design Intervention

The process mapping or RCA session may generate some early ideas for interventions; if more ideas are needed, a team brainstorming session may be helpful (Figure 18-3). The intervention should be sustainable, able to be brought up to an organization-wide scale, and have buy-in from key stakeholders. Teams should learn from experience in designing their interventions and take into consideration best practices and proven strategies. However, it is important to be open to diverse ideas from team members. Interventions can be graded by their potential impact. Sometimes, an intervention that is more difficult to implement at the outset—because it involves more team members or changing workflows and protocols—can have the most impact in the long run.

Olivia's smoking cessation team generates the following distinct intervention ideas:

- Option 1: Designate a current staff member from the behavioral health staff to become trained in smoking cessation counseling and implement a warm handoff model from PCPs for interested patients.
- Option 2: Educate all providers in how to prescribe nicotine replacement medication and adjuvant medication treatment.
- Option 3: Implement a medical assistant workflow protocol: medical assistants will screen for smoking status and offer smokers information about a free 800-number for smoking cessation counseling.
- Option 4: Have the clinic's smoking cessation handouts translated into Chinese and Spanish. Ideas they consider but reject for now include group visits for smokers, which is impractical given space limitations.

After a team meeting in which they discuss the potential impact of all the interventions and the perspectives of key stakeholders, the team decides to try option no. 1, the training of staff members from the behavioral health team

in smoking cessation counseling. Their decision is partly informed by knowing that the clinic management leadership team will support the dedication of staff time to this initiative.

The QI team notes that local data indicate that their Asian men and African-American patients have the highest smoking rates. They discuss how to ensure that their intervention reaches these groups. They decide to prioritize training for their Cantonese-speaking behavioral health team member. Given the data on the greater effectiveness of interventions targeted in culturally appropriate ways for specific groups, they seek out a training module that includes tailored information evidence-based strategies for counseling with diverse populations.[40,41]

Perform Iterative Cycles of Improvement

In order to test whether an intervention is effective, it is critical to implement small, iterative pilots or "PDSA" cycles: plan, do, study, act (Figure 18-4). Initial PDSA cycles should start small. For example, piloting an intervention with a limited number of providers first could allow workflows to be streamlined. The "study" involves collecting data from the pilot. However, unlike research, these data do not have to be blinded and carefully planned. Even a qualitative 15-minute discussion with involved staff members after a trial would suffice. For projects with an aim to decrease disparities as well as improve metrics for the whole patient population, the study phase needs to collect and analyze data on the impact by patient characteristics such as race and ethnicity. If preliminary evidence indicates that the intervention may not be effective in target groups, adjustments can be made to the intervention prior to the next cycle. Acting involves enacting any necessary changes to improve the intervention. If no change is necessary, the "A" can involve a scale-up of efforts.

Communicate Progress to Stakeholders and Team

As the PDSA cycles progress, communication of progress should be shared with stakeholders. This can be accomplished in many ways: in-person meetings, e-mail updates, and/or individual feedback. Posting charts, graphs, and other visual depictions of progress is one mechanism of sharing progress. A run chart can share the metric used to follow improvement, and to show historical trends and demonstrate progress to a goal. The run chart can also separate data into subgroups (e.g., by race and ethnicity)

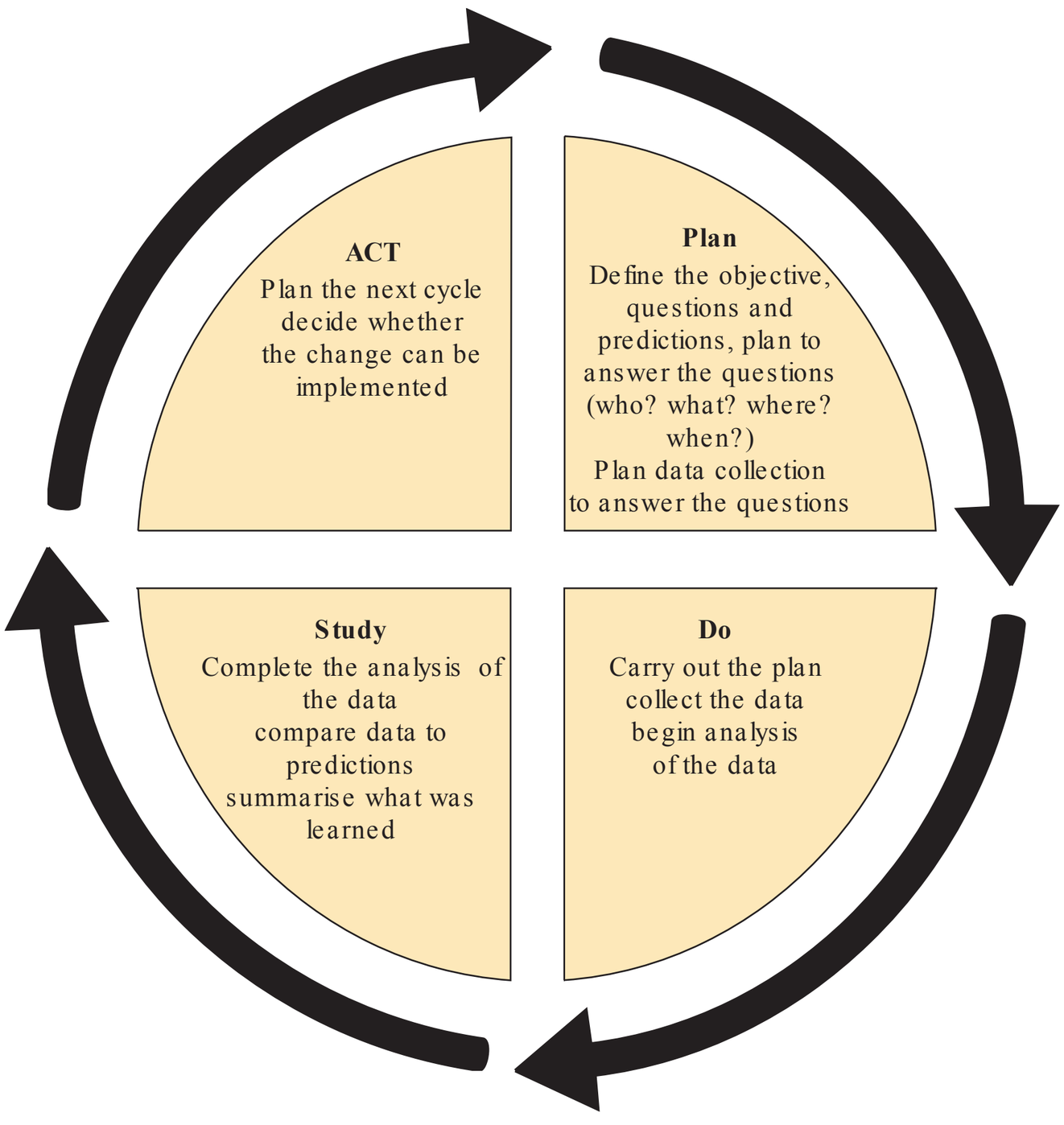


Figure 18-4. Institute for Healthcare Improvement's rapid change cycle (PDSA cycle): PDSA cycles are a critical step in implementing new initiatives.

to reveal the effect of the initiative on vulnerable patients as well as on the overall patient population.

CONCLUSION

Quality improvement is an important tool to use in settings with vulnerable patient populations. Appropriate data collection and analysis and thoughtful, team-based approaches to designing and implementing interventions can improve quality of care, cost, and patient experience in vulnerable groups as well as at a population level.

- Quality improvement refers to efforts to improve patients outcomes and health system practices by targeting health-care processes.
- QI efforts may reduce or exacerbate health-care disparities.
- QI efforts should take the specific needs of vulnerable patient groups into account from the start.
- QI that also targets health-care disparities should be based on data collection and analysis, which could include the collection of race, ethnicity, and language (REAL) data.
- A multidisciplinary team, including patients, that gathers input from stakeholders is the preferred way to choose and implement QI project.
- Repeated QI cycles are usually necessary to tweak processes and sustain gains.

Analyze Current Workflow (Step 4)

- Workflow (or process) mapping can be done with computer programs, or with a simple wipe board or a flip chart with sticky notes.
- Assemble multidisciplinary group with in-the-trenches experience with the process.
- Have each individual contribute to the portion of the process they know best.
- Create the map based on everyone's input, to a small level of detail.
- Review the map as a group highlighting key areas for improvement.

DISCUSSION QUESTIONS

1. A health plan decides to improve its flu shot rate by sending postcard reminders to all elderly patients. How might this approach improve flu vaccination rates? How might it fail? What else would you like to know before implementing this approach? After discussing this question, see Schneider, http://jama.jamanetwork.com/article.aspx?articleid=194224, for a discussion of managed care plans and African-American flu disparities.
2. A clinic examines the diabetes control rate of its Latino patients. Should it stratify those patients by English proficiency? What about stratifying by the Spanish-speaking ability of the clinicians? What might this approach elucidate? See Fernandez, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3019330/.

RESOURCES

The Institute for Healthcare Improvement is a national organization that has taken a leadership role in creating large-scale QI collaboratives and initiatives. IHI also has multiple conferences, training programs, and online learning resources such as the IHI Open School. For more information:

http://www.ihi.org/Pages/default.aspx

http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementEstablishingMeasures.aspx

http://www.ihi.org/education/ihiopenschool/

LEAN is a QI strategy that applies strategies from the Toyota Management System to health-care systems improvement. Many health-care organizations have transformed their operations and culture by using a LEAN approach. For more information:

Graban, Mark. Lean Hospitals: Improving Quality, Patient Safety, and Employee Engagement.

http://www.leanblog.org/eight-types-of-waste-in-healthcare/

Jackson, Thomas. Kaizen Workshops for Lean Healthcare

Intermountain Health Care is an example of an organization that uses QI principles throughout its organizational system and has been remarkably successful in its outcomes. Intermountain also leads intensive QI training programs for interested organizations and individuals. For more information: http://intermountainhealthcare.org/qualityandresearch/institute/courses/Pages/home.aspx

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Chapter 19

Interdisciplinary Models of Care for High-Risk Patients

Michelle Schneidermann, MD and Elizabeth Davis, MD

Objectives

- Review the limitations of "one-on-one" model of care for socially complex, chronically ill patients who are frequently admitted to the hospital.
- Describe the key components of interdisciplinary models of care for high-risk patients
- Review case studies of interdisciplinary programs for high-risk patients.

INTRODUCTION

Five percent of patients account for 50% of health-care costs.[1,2] These patients are often poor and have high rates of chronic disease, mental illness, and/or addiction.[2,3] Even when health-care services are readily available, many patients face multiple barriers to effective care such as homelessness,[4] low literacy,[5] social isolation,[6] language barriers,[7] addiction,[8] and mental illness.[9] These barriers to health care result in high rates of emergency department care and hospitalization, which drive the high costs of care in this population.[1,2]

There are many interdisciplinary models of care in the United States that have successfully decreased utilization and cost for patients at high risk for frequent hospitalization. They all include interdisciplinary teams in which both medical and nonmedical professions partner together to improve care for patients. Team members may include physicians, nurses, nurse practitioners, social workers, physical and occupational therapists, community health workers, health educators, pharmacists, psychologists, and other health professionals. These teams proactively identify the highest risk patients, create an interdisciplinary care plan that includes care coordination, and monitor how each patient is meeting the care plan goals.[1] These innovative, interdisciplinary models of care improve outcomes and costs by helping patients overcome personal vulnerabilities as well as social and health system barriers to effective care.[2]

This chapter discusses the concepts underlying these interdisciplinary models of care for high-risk patients, and describes specific programs. While the concept of providing interdisciplinary care for high-risk patients underlies all of these models of care, the different models may use different words to describe their work. Case management, complex care management, ambulatory intensive care units (ICUs), and care coordination are all terms that individual programs use to describe their work improving outcomes for high-risk populations using interdisciplinary teams. Throughout this chapter, we use "interdisciplinary models of care" to describe all of these types of programs. However, in each case example, we use the particular words that each program uses to describe itself.

FAILING CURRENT CARE

> Mr. Beltran is a 56-year-old man who works as a day laborer but is unable to find a steady job. Living in homeless shelters, he becomes increasingly depressed, and begins to drink heavily. After visiting the emergency room and being diagnosed with diabetes, he is referred to the resident clinic at the

county hospital. Here he has difficulty attending scheduled appointments with his primary care provider because of his unpredictable work schedule and his alcohol addiction, so he drops into clinic only when he is sick. In these visits, physicians who do not know him well adjust medications that are rarely filled, order laboratory tests that are rarely drawn, and write "lost to follow-up" over and over in the chart. The clinic nurse refers him to a Spanish-speaking social worker; he does not qualify for financial benefits because he is not disabled, and there are no options for subsidized housing.

After 10 years of intermittent outpatient care, Mr. Beltran is hospitalized many times with recurrent episodes of diabetic ketoacidosis, chronic diarrhea, pancreatitis, chronic pain, and bladder obstruction requiring an indwelling Foley catheter.

After each hospitalization, he is discharged to the streets with follow-up in the resident clinic. Living on the streets with an indwelling catheter, chronic diarrhea, uncontrolled diabetes, and little access to food, water, and sanitation, Mr. Beltran is admitted to the ICU with urosepsis.

Mr. Beltran's story raises many questions. Why is he requiring frequent hospitalizations and becoming more ill despite access to primary care? What could his primary care physician do to increase the effectiveness of the medical care Mr. Beltran is receiving? What could other models of care offer him that the current system does not?

Conventional medical care often consists of short appointments, spaced months apart with a primary care clinician who must address multiple problems. This model works well for many people. However, for some people with chronic diseases—certainly for those who suffer from poverty, mental illness, or drug addiction—this model is fraught with challenges for patient and clinician alike.

The 5% of people in the United States who account for 50% of health-care costs share similar characteristics with Mr. Beltran—they often have complex medical problems, are poor, and have mental illness and/or addiction.[1,2] In many areas, patients such as Mr. Beltran do not have access to primary care, but a study in San Francisco showed that in this locality, patients similar to Mr. Beltran actually had very high rates of contact with the health-care system, yet they were not in treatment for addiction, and continued to be seen frequently in the emergency department and admitted to the hospital.[10]

Even though these patients' needs are not being met by the current health-care system, what they need to be healthier and stay out of the hospital is understandable. In Mr. Beltran's case, access to housing, a bathroom, and food may have prevented his ICU stay. For other patients, durable medical equipment, ongoing one-on-one self-management coaching in the patient's native language, transportation, or medication delivery could significantly improve their health. Given the high rates of chronic disease, mental illness, and addiction in high-risk populations, the lack of integration between services for these problems creates often insurmountable and unnecessary barriers for these patients.[2]

Systems Factors

- Poorly integrated medical, psychiatric, and addiction services.
- Social services are either unavailable or operate independently from medical care, leading to gaps and redundancy in care.
- Insufficient self-management coaching leaves patients without the resources to manage their chronic conditions.
- Inadequate support with complicated medication regimens leads to medication errors and nonadherence.
- Poor access to transportation may limit patients' ability to follow-up.

Patient Vulnerabilities

- Competing personal priorities (the search for food, housing, and safety) interfere with accessing medical care.
- Mental illness and/or substance use interfere with patients' abilities to follow through on treatments and appointments.
- Lack of social support makes self-management challenging and reduces capacity to adapt to stressors.
- Poor access to sanitation and hygiene makes some patients embarrassed to seek care.

Provider Factors

- Providers are overwhelmed by the patient's complex social situation and doubt that the social issues can improve.
- Providers fail to recognize and leverage patient's strengths and resiliency factors.
- Overcoming language differences between patient and provider may prove too cumbersome for both patient and providers.
- Real or perceived cultural biases may impede effective alliances between patients and providers.

WHAT IS THE HISTORY OF INTERDISCIPLINARY MODELS OF CARE FOR HIGH-RISK PATIENTS?

Interdisciplinary models of care for high-risk patients evolved out of two very distinct challenges to health care: (1) the deinstitutionalization of severely mentally ill

patients in the 1960s and 1970s with the closing of mental health facilities and (2) the increasing costs of frequently hospitalized chronically ill patients in the 1980s.

In response to deinstitutionalization, interdisciplinary community-based programs focused on the severely mentally ill were created to provide a full range of services, from housing to psychiatric care for these patients. In response to the rising costs of caring for frequently hospitalized chronically ill patients, the Centers for Medicaid and Medicare Services (CMS) launched demonstration projects among Medicare recipients: nurse case management focused on specific chronic diseases, such as congestive heart failure, improved care for patients with those diseases.[2]

These two innovations in health care led, in the 1990s, to Health Maintenance Organizations (HMOs) adopting elements of CMS nurse case management in an attempt to control health-care costs, often hiring outside vendors to provide nurse case management telephonically to their members who had specific diseases. Ultimately, these HMO and vendor programs were unsuccessful in improving chronic disease care or controlling costs.[11] Lessons gleaned from this experience were that models work better when they are more tightly linked to primary care and include an in-person element.[12,13]

Complex care management evolved to focus on patients with multiple diseases, rather than just a single disease, who were at high risk of hospitalization. This evolution was driven by the success of the CMS demonstration programs, the failure of vendor disease management, and the changing incentives in health care.[12,14]

> Mr. Beltran survived his hospitalization and was referred to a high-user case management program. A Spanish-speaking case manager finds him a respite bed in a shelter. The registered nurse in the program puts together a medi-set that is delivered on a weekly basis. He is also reminded of his medical appointments and escorted to them by a team member. His primary provider adds antidepressants and nutritional supplements to his treatment. Eventually, permanent housing in a senior supportive housing facility is found for him. He is taught to use a glucometer and to straight catheterize himself. After a few months in the program, he has no further hospitalizations.

HOW DOES IT WORK?

EFFECTIVE TEAMWORK

In 2001, the Institute of Medicine's Committee on the Quality of Health Care issued a report in which a major theme was the importance of using teams to deliver quality care to patients.[15] Physician education, training, and testing are just beginning to include education in working on teams. Evidence suggests that effective teamwork does not arise spontaneously, but rather requires specific skills and development.

People tend to think of a team as simply being a group of people working together, but as one observer noted, "It is naïve to bring highly skilled professionals together and assume that, by calling this group a team, it will act like a team."[16]

Common barriers to working well as a team are goal conflict, role conflict, and poor decision making (see "Core Competency"). A high functioning interdisciplinary team has been defined as "a group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve patient problems that are too complex to be solved by one discipline or by many disciplines in sequence. Team members determine the team's mission and common goals: work interdependently to define and treat patient problems; and learn to accept and capitalize on disciplinary differences, differential power and overlapping roles."[17]

In the context of care models for high-risk patients, interdisciplinary teams may include a large range of medical and nonmedical professionals. Assistance linking to public assistance programs, state and federal health insurance, housing, transportation, and food resources may be as important as links with medical and psychiatric care. Each member of the team addresses different aspects of patient care, working together toward a common goal for which they take joint responsibility. High-functioning teams can reach a level of synergy that enhances effectiveness and efficiency.[18]

PROGRAM DESIGN

These programs typically share a basic structure: a process for identifying high-risk patients, a comprehensive assessment, an interdisciplinary care plan, and a method of tracking progress toward care plan goals.[12] Their overarching mission is to improve patients' health and avoid hospital and emergency department use. Successful programs customize their model to the local context, focus on building trusting relationships with patients, provide in-person care including home visits, train their staff specifically about complex care management, are linked to primary care, and use a coaching philosophy with patients.[12,14,19,20] Activities of interdisciplinary teams within these programs include support with housing, transportation, medication management, self-management coaching, mental health care, addiction services, and care coordination.[2,3]

Programs use multiple approaches for identifying patients, with the goal of identifying patients who are at

Box 19-1. Interdisciplinary Care Models Process Variables

- Duration of services
- Intensity of services (frequency of patient contact and patient–staff ratios)
- Focus of services (varied degrees of behavioral and medical focus)
- Availability (from scheduled office hours to 24-hour availability)
- Location of services (from all services delivered in a clinical office to all delivered in the community or home)

high risk of future hospitalization and whose needs can be met by the program model. Patient's risk can be assessed quantitatively (i.e., by using predictive modeling or prior utilization data), qualitatively (i.e., provider referral), or both. Using an identification model that combines quantitative and qualitative methods, such as identifying patients with predictive modeling software and then asking providers to refer patients from that list, may be the most successful.[21] Once high-risk patients are identified, programs must determine if each patient is well served by the program model. For example, a homeless patient with severe mental illness and addiction may not be well served by a model that does not have adequate behavioral health support.[21]

These programs vary widely in their program structures and team compositions (Box 19-1). Some designs are more behavioral health focused, such as those with expertise in addiction or mental health, while others are more medically focused, emphasizing self-management and medication management. Lead organizations for these programs may be practices, health plans, departments of public health, community organizations, or employers; different programs serve different populations. Services may be delivered on the street, at primary care practices, or at hospitals, and vary in their duration and intensity.

EXAMPLES OF INTERDISCIPLINARY MODELS OF CARE

Interdisciplinary models of care for high-risk populations share the overall goal of improving health and reducing hospitalizations and emergency department visits. However, the specifics of each program are tailored to the local populations that each program serves. There is no one-size-fits-all solution.

ASSERTIVE COMMUNITY TREATMENT

The oldest and most well-studied approach is assertive community treatment (ACT). The ACT model was developed in the 1960s in response to the closing of psychiatric hospitals. In these models, community-based, interdisciplinary teams of psychiatrists, nurses, social workers, addiction counselors, psychologists, community health workers, and vocational rehabilitation workers provide direct treatment, rehabilitation, and support services to severely mentally ill patients. The goals are to minimize referrals to outside providers, provide services on a long-term care basis, deliver the vast majority of services in the community, and be available 24 hours a day.[22,23]

Evaluation of the ACT approach has found that ACT programs result in few psychiatric admissions, better independent living skills, improved symptomatology, enhanced work and social functioning, and high consumer satisfaction.[23,24] The Center for Mental Health Services within the US Department of Health and Human Services has published evidence-based standards for ACT programs. Cost-effectiveness studies of ACT programs have shown either cost savings or cost "neutrality."[25,26]

SAN FRANCISCO GENERAL HOSPITAL CASE MANAGEMENT PROGRAM

Responding to the body of evidence that emerged about ACT program successes with high users of psychiatric services, San Francisco General Hospital pioneered two intensive case management programs in the 1990s to address the needs of patients who frequently required hospital inpatient and emergency services. These programs used interdisciplinary teams including an internist, a psychiatrist, nurses, and social workers. In this model, each social worker assisted the 15 to 20 patients in his or her case load with everything from attending medical appointments, getting medications and treatment for mental illness or drug use to receiving entitlements (such as Social Security Income) and finding housing. Patients were followed up closely in the hospital and out in the community, and the team assisted with communication among the many providers involved in their care. Evaluations of these programs showed not only significant decreases in hospitalization but also decreases in cost of care.[10]

After the success of the San Francisco General Hospital programs, a California-wide initiative spread similar programs across the state, with reductions in utilization and costs.[3] Many other programs across the country have also been successful.

COMMUNITY CARE OF NORTH CAROLINA

In North Carolina, a statewide Medicaid complex care management program called Community Care of North Carolina featured nurses, social workers, and paraprofessionals who had pharmacy and psychiatric support. Care

managers were embedded in primary care practices, and focused on the highest utilizing 5% of Medicaid patients in the state. An analysis showed that this program reduced admissions by 20%, and saved the state an estimated $984 million dollars over 4 years.[1]

CHICAGO HOUSING AND CASE MANAGEMENT TRIAL FOR HOMELESS ADULTS

In Chicago, a randomized controlled trial focused on homeless patients hospitalized with complex medical conditions and found that patients who received housing after discharge from the hospital with intensive case management at the housing site had 29% fewer hospital days and 24% fewer emergency department visits over 18 months. In this study, case management was provided by a masters level social worker who worked with an interdisciplinary team focused on housing, connection to social services, and coordination of medical care.[27]

CAMDEN COALITION

In Camden, New Jersey, Jeffrey Brenner has led the Camden coalition to identify high-risk, high-cost patients through use of hospital data and to provide complex care management to those patients, including an interdisciplinary team that provides home visits and provides linkages to primary care. In a pre-post analysis, after enrollment in the program, patients had 40% lower utilization of the hospital and emergency department and 50% lower costs.[28] Brenner is now spreading his model to other sites across the United States.

ONE MILLION COMMUNITY HEALTH WORKERS CAMPAIGN

Internationally, case management has emphasized the roll out of community health workers, such as through the One Million Community Health Workers Campaign. Community Health Workers (CHWs) not only provide successfully primary care functions such as immunization but they also provide maternal and child health care and chronic disease care, particularly for malaria, tuberculosis, and HIV.[29,30] In Rwanda, CHWs working with health-care teams have had very high rates of successful tuberculosis treatment and adherence to HIV treatment.[31]

AMBULATORY INTENSIVE CARE UNIT MODEL

Another approach to frequently admitted patients is the Ambulatory Intensive Care Unit (AICU) model developed by Arnold Milstein.[32] In this model, high-risk patients receive all of their care at an AICU, which features intensive primary care, health coaching, interdisciplinary teams, medication management, and efficient utilization of specialty services.

Most of the programs utilizing this model have been employer based —such as Boeing, Stanford, and the Atlantic City Casino Workers Union. However, Hennepin County Medical Center, a safety-net hospital, launched an AICU for frequently hospitalized underserved patients in the Minneapolis area. A pre-post analysis showed that after patients enroll in the program, they have a 50% decrease in hospital admissions and emergency department visits and a 23% reduction in costs.[1]

All of these programs feature integration at the systems level. In the North Carolina model, interdisciplinary teams hired by the Medicaid health plan were physically located in the primary care practices; the Chicago program linked housing, social services, and medical care; in AICU models, the care was centralized and fundamentally redesigned. Through integration at the systems level, the programs were able to overcome unnecessary barriers that patients faced, such as lack of housing, lack of medication management support, and lack of transportation, to name a few. Without organizational support and integration, team members would not have been able to obtain the resources necessary for patients to improve their health and reduce utilization.

WHAT IS THE BUSINESS CASE FOR IMPROVING THE HEALTH OF FREQUENTLY HOSPITALIZED PATIENTS?

Improving health and reducing utilization are important goals, but what is the business case for creating interdisciplinary programs focused on these goals? While reducing health-care costs broadly is a nationwide focus, in a traditional fee-for-service model, hospitals get paid for hospitalizations, so hospitals could lose revenue if these programs are successful. For patients who are uninsured or insured publically, however, reimbursements may still not cover the costs of care. In the era of the Affordable Care Act, there are multiple mechanisms to incentivize these programs.[33] Some payers, including Medicare, pay practices a monthly payment for providing complex care management services to members. In Accountable Care Organizations (ACOs), risk for hospitalization is shared and savings are shared as well, so programs that reduce preventable hospitalizations save money for all parties. In fact, almost all provider groups who share risk as part of their ACO contracts have launched complex care management programs.[13] Incentive-based payments, which provide payments based on quality care, such as timely follow-up after discharge or low readmission rates may also spur creating these programs. For Medicare patients, hospitals are being penalized for excess readmissions, a trend that may spread to Medicaid and other payers.

This changing landscape of financial incentives has led health plans, hospitals, and primary care practices to rapidly launch interdisciplinary programs for frequently hospitalized patients throughout the United States.

CONCLUSION

A small percentage of frequently hospitalized patients account for a disproportionate share of health-care costs. These patients are often poor and have chronic diseases, mental illness, and/or addiction. The medical care that these patients do receive is often inadequate and does not meet their needs. Recognition that we are failing to care adequately for the sickest patients has led to the development of interdisciplinary models of care that seek to reduce utilization and improve health for these patients by addressing patient, provider, and systems level factors. These models recognize the social and medical ills that complicate patients' health and they also acknowledge that no single provider can provide adequate care alone. Although no panacea, these programs offer patients and clinicians additional resources and multiple professional perspectives that can help tackle complex situations. These programs are often successful in reducing utilization and, perhaps ultimately, in improving the health of high-risk patients.

In interdisciplinary Care Models for High-Risk Patients

- A small number of patients account for a disproportionate share of health-care costs, largely due to frequent hospitalizations.
- These frequently hospitalized patients have high rates of poverty, chronic disease, mental illness, and addiction.
- Interdisciplinary models of care can successfully improve the health of these patients and reduce utilization.
- Interdisciplinary teams provide perspectives from multiple professions and reduce barriers to adequate care at the system, provider, and patient level.
- There is no one-size-fits-all approach; each program must be tailored to the local population.

Dealing With and Avoiding Conflict When Working in Teams[29]

Avoiding goal conflict

- Clearly identify members of the team.
- Clearly identify goals (including short term, long term, and maintenance).
- Achieve consensus around priorities.
- Formulate action plans.
- Have all members of the team agree on action plan and follow-up steps.

Avoiding role conflict

- Clarify expectations of each team member.
- Identify professional competencies (including skills and education).
- Explore role perceptions.
- Explore overlapping responsibilities.
- Negotiate role assignments.
- Review and agree on responsibilities in carrying out action plans.

Effective decision making

- Explicitly define the problem.
- Clarify member roles and involvement in decision.
- Obtain and provide relevant data to all team members.
- Obtain input from all relevant team members.
- Generate a "differential diagnosis" for treatment; that is, multiple options and alternatives.
- Test various options.

DISCUSSION QUESTIONS

1. Think of a patient you have seen recently who has been frequently hospitalized. Could this patient benefit from an interdisciplinary team? What could each discipline bring to the care of this patient?
2. What interdisciplinary programs are available in your clinical setting that focus on frequently hospitalized patients? How are they organized to improve care? In what ways are they successful and in what areas could they improve?
3. How should medical education change to create physicians effective at interdisciplinary collaboration?
4. Can you think of a time when role conflicts or goal conflicts interfered with a patient's care? How might you manage team dynamics differently the next time you encounter a similar situation?

RESOURCES

The California Health Care Safety Net Institute is committed to advancing community health for California's low-income, racially and ethnically diverse populations. http://www.safetynetinstitute.org/.

The National Health Care for the Homeless Council works to reduce homelessness through providing housing and healthcare for all. http://www.nhchc.org.

The mission of the DC Area Health Education Center is to improve the health status of the disadvantaged residents in the District of Columbia. This module is designed to assist the student in gaining an increased understanding and

appreciation for interdisciplinary health-care team practice. http://dcahec.gwumc.edu/education/session3/.

RAND Health's goal is to advance understanding of health and health behaviors, and examine how the organization and financing of care affect costs, quality, and access. http://www.rand.org/health/.

Assertive Community Treatment Association promotes, develops, and supports high-quality Assertive Community Treatment (ACT) services that improve the lives of people with serious and persistent mental illness. http://www.actassociation.org/. The Agency for Healthcare Research and Quality Innovations Exchange is a searchable database of innovative programs and tools to improve healthcare. http://www.innovations.ahrq.gov/.

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PART 3

Populations

CHAPTERS

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Chapter 20

Underserved Children: Preventing Chronic Illness and Promoting Health

Patricia Barreto, MD, MPH, Joanna Mimi Choi, MD, and Neal Halfon, MD, MPH

Objectives

- Review emerging definitions of children's health and changing epidemiology.
- Define health development and discuss the impact of the social environment on health outcomes.
- Identify protective factors for child health development.
- Define health promotion and describe the Life Course Health Development Model.
- Describe the unique vulnerability of children.
- Identify strategies to transform the clinical practice to serve vulnerable children.
- Summarize strategies to tailor clinic-based assessment, education, intervention, and care coordination to vulnerable children.

Xavier is a 2-year-old boy with delayed language development. His parents are immigrants from Mexico and speak to him in Spanish. He watches television 3 hours a day and reads with his parents two to three times per week. His parents describe him as a normal, healthy boy.

INTRODUCTION

Childhood is a critical and dynamic period of health development that has lifelong effects on health and well-being.[1] Preventing chronic illness and promoting optimal long-term health require a special focus on optimizing health and overall functional capacity in childhood, investing in a child's health potential and lifelong health reserves.

This chapter discusses emerging concepts of children's health and highlights the relationships among health, health development, and health promotion. It proposes a framework for understanding health development over an individual's lifetime[2] and how pediatric health-care providers can promote health and prevent chronic illness in the child and the future adult.

EMERGING CONCEPTS IN CHILDREN'S HEALTH

The 2004 Institute of Medicine (IOM) report, Children's Health, the Nation's Wealth, defines children's health as "the extent to which an individual child or groups of children are able to or enabled to (a) develop and realize their potential; (b) satisfy their needs; and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments."[3] This definition of children's health highlights the intimate relationship between health and human development and expands it to include not only physical but also social and mental well-being. Furthermore, this definition focuses not only on the individual child but also on groups or populations of children.

US child health ranks at the bottom among wealthy nations in the Organization for Economic Co-operation and Development (OECD)/UNICEF rankings, partially explaining why the United States is the sickest of wealthy nations as measured by adult health outcomes.[4,5] This is not surprising given that in just one generation, we have witnessed remarkable increases in child health problems, with over 30% of all children having chronic health conditions. Nearly 10% of all children report disabilities caused by health problems (up from 2% in 1960) and 22% of adolescents report diagnosable mental health conditions with impairments.[6,7]

CHANGING EPIDEMIOLOGY

The shifting epidemiology of child health has profound implications for how children's health care should be organized and delivered. Prior to the 1970s, infectious diseases were the dominant threat to children. With advances in vaccine effectiveness and availability, as well as other public health improvements, the focus of clinical pediatrics in the United States has shifted to the prevention, identification, and management of chronic health conditions, such as asthma and obesity, as well as neurodevelopmental conditions, such as attention-deficit hyperactivity disorder, anxiety, and depression.[6,8,9] Despite this major shift in the epidemiology of child health, much of the organization of pediatric well child care continues to focus on the prevention of infectious disease and the provision of immunizations.[10] A major challenge now is addressing the mismatch between the current way that children's primary care is organized and the changing epidemiology of child health.[10,11]

CHILDHOOD POVERTY

Living in poverty has always been associated with greater exposure to adversity, more risks, and decreased access to resources including health care. The US social landscape was characterized by rising social mobility and a general trend of decreasing inequality for many decades (1910s-1970s).[12] This created an atmosphere where the American Dream—that each generation of Americans would be better off than the previous generation—was an ostensible reality, and it supported a view that poverty was not a permanent life course exposure.

After nearly five decades of increasing social mobility, education expansions, and additional benefits provided by War on Poverty programs, child poverty rates were cut from 27% to 14% between 1960 and 1975.[13] However, household poverty rates of families with children began to increase in the late 1970s and, other than a slight downturn during the 1990s, have persisted at high levels. Currently, 22% of children live in families whose income is below the federal poverty line (FPL), with almost half (45%) living below 200% FPL.[12,14] Overall, the current lack of social mobility means that 40% of kids born into the lowest quintile of income (i.e., poverty) will continue to live below the lowest quintile their entire lives.[15] This trend is especially concerning as a growing body of literature suggests most low-income families (i.e., living below 200% of FPL) do not have the economic resources nor the access to the services and supports that are necessary for their children to thrive.

With deeper social stratification and a steeper social gradient, even families that are still considered middle class are finding that they do not have the time and resources necessary to provide all the child rearing resources that their children need.[16] Overall, with inadequate support for child care, early intervention services, and other child rearing supports commonly the norm in other nations, families also lack the services that they need to help their children thrive.[17]

HEALTH DEVELOPMENT AND IMPACT OF THE SOCIAL ENVIRONMENT ON HEALTH OUTCOMES

Health development is a term that further expands the definition of health to acknowledge childhood as a unique period in which biological, behavioral, and environmental influences intertwine to influence current and future (adult) health.[2,18,19] For example, in children with asthma, environmental exposures (e.g., dust mites, smoke) cause chronic inflammation and ultimately change lung structure and function, which has implications for adult lung function and adult functional capacity. Interventions improving children's health thus can potentially prevent lifelong chronic illness.

Health development also defines health in terms of functional capacity. In so doing, it recognizes that health is a dynamic state that is influenced by multiple determinants, from genes to the environment with which they interact.[2] For example, a poorly nourished child from a low-income family who is exposed to violence and attends school in an overcrowded classroom may not reach his developmental potential and is at greater risk for anemia, injuries, and behavioral problems. If these result in lower educational achievement, the path out of poverty becomes more difficult to follow.

Recent data highlight the relationship between low SES/poverty and brain development, including areas such as the prefrontal cortex and hippocampus, providing a biological explanation for how environmental stressors associated with poverty "get under the skin" and have lasting impacts on functional outcomes.[20-24] For example, "toxic stress" can affect a child's developing midbrain and interrupt affiliation and attachment capacities, affect the prefrontal cortex, and interfere with the development of optimal executive function. This results in decreased

impulse control, which affects not only interpersonal behavior but also the ability to control one's choices.

Furthermore, evidence from the Adverse Childhood Experiences (ACE) study suggests that stressors/adverse childhood experiences are both highly prevalent and associated with adult comorbidities, including cardiovascular disease, chronic lung disease, chronic liver disease, depression, mental illness, obesity, smoking, and alcohol and drug abuse.[25]

These examples underscore that poverty/adverse childhood experiences perniciously stymie a child's capacity to achieve his maximal potential and has implications for adult health. Termed "double jeopardy" by some, poverty presents both a multitude of risks undermining optimal health development and a dearth of resources to mitigate them.[26]

PROTECTIVE FACTORS FOR CHILD HEALTH DEVELOPMENT

Some people are able to develop mechanisms to deal successfully with the risks they face, thus enhancing their health and well-being. This quality, referred to as resilience, is critical for attaining optimal functional capacity, especially in the face of adversity.[27-29] Factors contributing to resilience are often termed protective or promoting factors, and they may either be intrinsic to the individual (e.g., their temperament or disposition) or external (e.g., educational opportunities, a supportive family, social connectedness/support). Protective qualities can be found in the individual, the family, and the community, as well as through the relationships that emerge through interactions between these groups. Like risk factors (remember the example of poverty), protective and promoting factors often occur together. Health promoting and protective factors can be particularly important in mitigating the impact of stressful life events in vulnerable children, and some protective factors are more important than others for children at particular developmental stages[29] (Table 20-1). Supportive grandparents, siblings, teachers, and mentors can all play a role in buffering children from the effects of risk factors associated with poverty. However, poverty and its related stressors can erode a parent's ability to provide high-quality parenting.[30] Therefore, bolstering interpersonal relationships and high-quality parenting is one way that clinicians can promote health.[31]

Resilience in children can manifest in different ways and is dependent upon the child's ability to develop specific noncognitive skills, capabilities, and capacities. Older children and adolescents who embrace challenges persist in addressing difficult tasks in the face of challenges, learn from criticism and see effort as the path to mastery, develop a mindset with the capacity to succeed in spite of difficult circumstances.[32] Developing such skills, however, requires a sound emotional foundation in early childhood, the ability to communicate responsively with peers and adults, and the development of other capacities including executive function.[33]

Table 20-1. Individual-, Family-, and Community-Level Protective Factors

Protective Factors	Developmental Period
Individual	
Low distress/low emotionality	Infancy–adulthood
Active, alert, high vigor, drive	Infancy–adulthood
Sociability	Infancy–adulthood
"Easy" engaging temperament	Infancy–childhood
Advanced self-help skills	Early childhood
Average–above average intelligence	Childhood–adulthood
Ability to distance oneself, impulse control	Childhood–adulthood
Internal locus of control	Childhood–adolescence
Strong achievement motivation	Childhood–adolescence
Special talents, hobbies	Childhood–adolescence
Positive self-concept	Childhood–adolescence
Planning, foresight	Adolescence–adulthood
Strong religious orientation, faith	Childhood–adulthood
Family/community	
Small family size (<4 children)	Infancy
Mother's education	Infancy–adulthood
Maternal competence	Infancy–adolescence
Close bond with primary caregiver	Infancy–adolescence
Supportive grandparents	Infancy–adolescence
Supportive siblings	Childhood–adulthood
For girls: emphasis on autonomy with emotional support from primary caregiver	Childhood–adolescence
For boys: structure and rules in household	Childhood–adolescence
For both boys and girls: assigned chores: "required helpfulness"	Childhood–adolescence
Close, competent peer friends who are confidants	Childhood–adolescence
Supportive teachers	Preschool–adulthood
Successful school experiences	Preschool–adulthood
Mentors (elders, peers)	Childhood–adulthood

Examples of protective factors that have been identified in two or more longitudinal studies of resiliency in children and youth. Source: Adapted from Werner E. Protective factors and individual resilience. In Shonkoff J, Meisels S, eds. Handbook of Early Childhood Intervention, 2nd ed. New York: Cambridge University Press, 2000:115-132.

HEALTH PROMOTION AND THE LIFE COURSE HEALTH DEVELOPMENT MODEL

> **Trajectory 1:** Projecting forward several years, Xavier has significant language delays when he goes to school. In first grade, his teachers become concerned, but it is not until third grade that he is tested and found to have language and cognitive delays. His family is disrupted when his father needs to return to Mexico; his mother works two jobs just to make

ends meet. His life is now affected by food insecurity, less parental attention, more screen time, and frequent housing moves. With poor grades and little support, he eventually drops out of school.

Trajectory 2: Xavier receives a comprehensive language assessment at age 2 and is placed in language and cognitive stimulation programs. His mother is supported through her local community center where they offer parenting classes and she learns parenting skills that foster her attachment with Xavier and promote his ability to self-regulate. Xavier attends a high-quality family-based child care center where he learns more socialization skills and has regular physical activity and planned healthy meals and snacks daily. He enters school with near-normal language function, normal body mass index, and cognitive and social development. He does well in school, particularly math and science. Although his father has to return to Mexico for a short time, his family receives additional assistance to maintain stable housing, food security, and consistent and supportive relationships with friends and teachers at school.

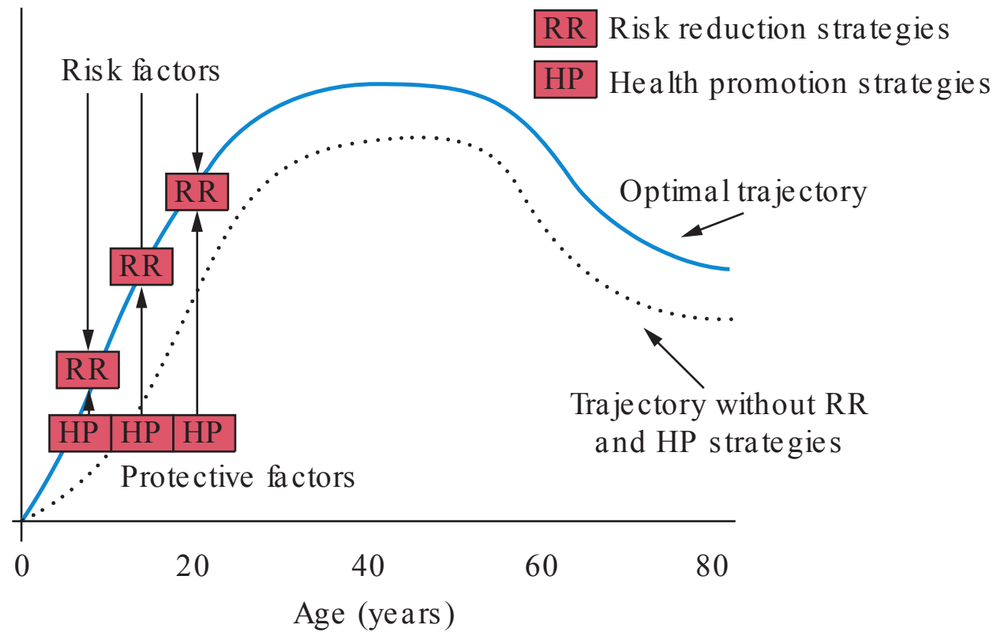


Figure 20-1. The health development trajectory: How risk reduction and health promotion strategies influence health development. This figure illustrates how risk reduction strategies can mitigate the influence of risk factors on the developmental trajectory, and how health promotion strategies can simultaneously support and optimize the developmental trajectory. In the absence of effective risk reduction and health promotion, the developmental trajectory will be suboptimal.[2]

Health promotion integrates broad definitions of health and development into health care to enable "individuals to increase control over and improve their health. It involves the population as a whole in the context of their everyday lives, rather than focusing on people at risk for specific diseases and is directed toward action on the determinants or causes of health."[34]

The Life Course Health Development (LCHD) model integrates the ideas that health develops over an individual's lifetime and is influenced by environmental, physiologic, behavioral, and psychological factors into an analytic framework useful for health providers for health promotion.[2,35] Positive or protective factors—genetic, environmental, or social—act to allow an individual to attain optimal healthy functioning. Negative influences on health, on the other hand, deter a person from achieving this potential. The balance of these forces determines the health trajectory of an individual (Figure 20-1).

Health professionals can have a significant impact on their patients' health by helping parents take steps to decouple the impact of adversity on their child's health development, providing services that can buffer the effects of different risks and by organizing interventions that provide the supportive scaffolding that promote optimal health development. The LCHD model frames health broadly and includes an ecological orientation that integrates the "upstream" social, environmental, and behavioral factors, influencing health in a way most often ignored by traditional medical models. Adoption of this framework requires a shift in clinical practice from major focus on the search for disease and disability to a perspective that also focuses on developmental assets and other factors that can be marshaled to enhance prevention and the active promotion of health.

Consistent with the life course orientation of Healthy People 2020[36] and a growing focus on the social determinants of health, the LCHD framework places special emphasis on the integration of the social determinants of health or non-biomedical factors (housing, income, access to healthy food, educational opportunity), thus acknowledging the special role that they play, especially during sensitive periods of development, on a range of significant health outcomes.

Viewed from the perspectives of LCHD, childhood represents an opportunity for health-care providers to intervene effectively to prevent disability and promote lifelong health during a developmental period in which interventions can be leveraged to improve the immediate health of children as well as the long-term health of the population as a whole. The integration of individual and population health promotion and disease prevention requires ongoing surveillance of the child and family functioning in order to identify strategic opportunities to support resilience and minimize risk. Finally, LCHD and the idea of health promotion provide powerful tools for tackling the vexing health problems of underserved children (Box 20-1).

THE VULNERABILITY OF CHILDREN

Children are uniquely vulnerable because they are rapidly developing and, as nonautonomous individuals, they are dependent on others for their health, safety, and well-being. Their vulnerability is dynamic because they

Box 20-1. Linking Children's Health Definition to the Life Course Health Development Framework and Changes in Clinical Practice

Transformation of the Concept of Children's Health
Moves away from disease-based model
Focuses on:
- Optimizing development and function
- Maximizing individual and population potential

Highlights:
- Interaction of environment, contextual factors, and the individual

Application of Life Course Health Development Framework
LCDH concept:
- Individual-, family-, and community-level risk and protective factors interact to influence the health development of individuals over their lifetime

LCDH model:
- Framework for understanding how health develops over an individual's life time
- Conceptual structure to promote health among vulnerable populations

The Transformed Clinical Practice:
- Serves as a service delivery hub connected to a wide array of community resources
- Uses community epidemiologic data to identify community-level health risk factors and guide development of targeted health service delivery pathways
- Uses asset mapping to identify community-level health protective factors and create external links to community-based organizations
- Tailors clinic-based assessment, education, intervention, and care coordination to vulnerable children

are changing and these changes are exquisitely sensitive to external pressures. Thus, anticipating sensitive developmental periods in which children may be more vulnerable based on both their developmental capacities and their contextual environment as defined by their family, school, and community is crucial.[19] Although all children are vulnerable, for some children this vulnerability is exaggerated by poor health, social or family circumstances, or other environmental threats, such as poverty and toxic stress.

- Applying a disease-based model for health care to vulnerable populations
- Ignoring the contextual or environmental factors that influence health
- Not addressing contextual factors and adaptive responses from a developmentally appropriate perspective
- Applying individual-focused health promotion strategies to vulnerable populations
- Overlooking the inherent vulnerability of children, the dynamic nature of vulnerability, and the need to intervene at developmentally sensitive periods
- Supporting clinical practice systems that are not organized to identify and intervene to support health protective factors and remove health risk factors
- Delivering clinic-based assessment, education, intervention, and care coordination that are not tailored to vulnerable patients

TRANSFORMING CLINICAL PRACTICE TO SERVE VULNERABLE CHILDREN

As noted earlier, current clinical service delivery mechanisms fall short in key areas, such as addressing children's developmental and other "nonmedical" (psychosocial, environmental, parenting) concerns.[37] These concerns are often directly linked to common morbidities (e.g., developmental delay, drug and alcohol abuse, mental and emotional disorders, family violence, and obesity) that challenge families and health care providers.[38] Although these psychosocial/environmental concerns undermine health, clinicians often feel unprepared and inadequately equipped to address them.[39] If they cannot offer a resource or potential solution to the family, clinicians may not inquire about issues such as domestic violence or other adverse childhood experiences, mental illness, homelessness, drug and alcohol abuse, hunger, access to high-quality child care, food insecurity, school performance, behavioral concerns, educational resources, or social isolation.[40,41]

In order to address economic disparities and the multiple forms of adversity associated with poverty, clinicians can advocate for social policies that decrease economic disparity and support families in rising from poverty.[12,17] The following suggests actions that health-care providers can take within his/her clinical practice to mitigate the impacts of these issues on an individual level.

MAKING THE CLINICAL PRACTICE THE SERVICE DELIVERY HUB

To effectively address the health risk and protective factors affecting children illustrated in the LCHD model (Figure 20-1), a clinical practice must function as a hub or resource center that is effectively linked to community resources. Figure 20-2 illustrates the four key components of primary care of children: acute care, chronic illness care, preventive care/health promotion, and developmental/behavioral health services.[31] The capacity of any provider to address the needs of vulnerable children and their families is not only determined by the knowledge, skills, and resources that are available within the clinical setting, but

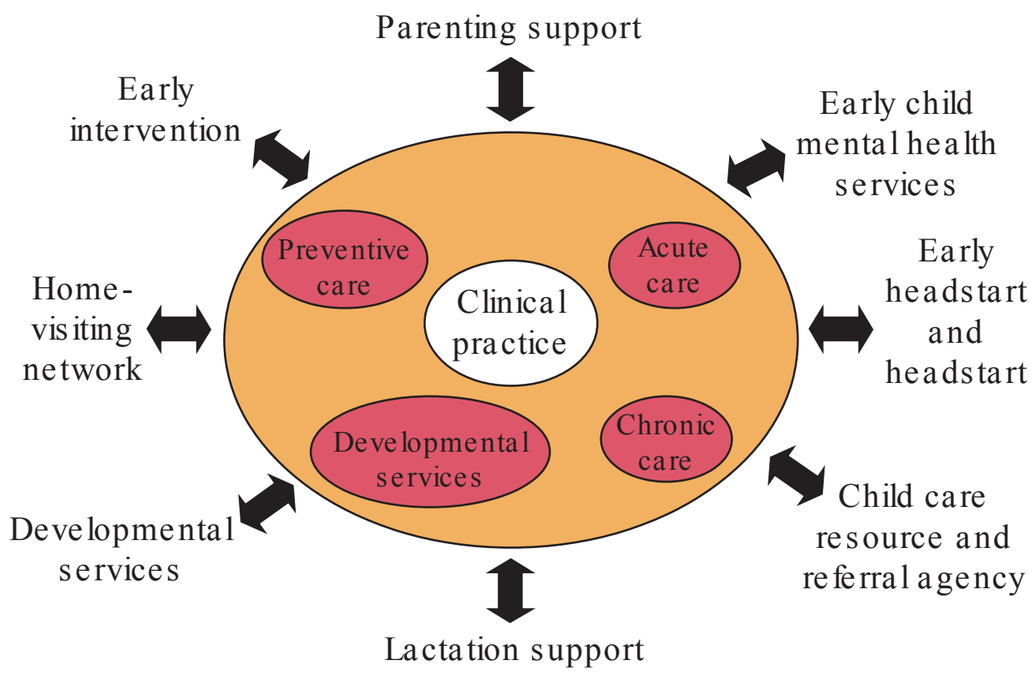


Figure 20-2. The pediatric office as a service delivery hub. The role of the clinical practice in the community. Adapted from Regalado and Halfon.[31]

also depends on their ability to link to other community-based resources and services such as early intervention services, child care resources, developmental services, healthy food options, and parenting support. The clinical practice is placed at the center of this service organization model because pediatric primary care providers have the unique opportunity to interact with families on a regular basis before school entry. The Patient-Centered Medical Home (PCMH) is an example of a delivery model that seeks to integrate the four components of primary care for children while also promoting access, coordination of care, and linkage to community resources.[42,43]

REVIEWING COMMUNITY EPIDEMIOLOGIC DATA

Review of community epidemiologic data is the first step in assessing the prevalence and distribution of risk in a community and in the identification of protective assets. Knowledge about these elements in the life of the community allows the clinician to create more individualized, context-driven assessments, education, and interventions to support individual health development (see Chapter 6). With the greater availability of geographic information system (GIS) mapping, many communities are developing neighborhood level maps of child health and developmental outcomes, measures of school readiness, and indicators of social and behavioral risk that can be used to begin to create a picture of the local ecological dynamics of health development.[44]

CONDUCTING ASSET MAPPING

The asset mapping process provides a more in-depth understanding of a community's protective factors. Asset mapping focuses on the assets of a community, including "individual assets (talent, time, experience, relationships), citizen's associations (grassroots organizations, community centers), and local institutions (schools, libraries)."[45]

Although a clinical practice may not have the time or resources to complete intensive asset mapping, an asset focus is vital to identifying and supporting community-level protective factors. Practices may gather information and catalog a list of resources for their patients. Over time a practice can develop robust linkages to community-based organizations (CBOs) allowing the clinic to address health risks and support health protective factors in the community.

Practices have found that strong relationships with key community partners (food bank, high-quality community centers/youth centers, parenting programs) are more useful than a list of potential but unknown resources. Furthermore, practices can systematically identify and support the individual assets in a family (e.g., positive parenting practices, involved grandparents or other family members, social connectedness, involvement in the child's education, maintaining healthy lifestyle routines with sufficient sleep, physical activity, and nutrition).

CREATING LINKS TO COMMUNITY-BASED ORGANIZATIONS

> The community health center has been building its relationship with local CBOs, one of which focuses on developing high-quality in-home day-care centers operated in the neighborhood and on supporting parents in developing positive parenting skills. There is a family day care in Xavier's neighborhood whose provider speaks Spanish. The CBO offers classes in positive parenting. In addition, the local library has a free story-time session three times per week including weekends. The local park has a safe play area for toddlers and a community garden.

Once a clinic has identified community-based resources, the next step is to create linkages to these organizations, allowing for open communication and referrals. The National Initiative for Children's Healthcare Quality (NICHQ) has developed a set of tools and procedures to help practices organize and improve health development–oriented care routines and administrative processes (see "Resources" section).

TAILORING CLINIC-BASED ASSESSMENT, EDUCATION, INTERVENTION, AND CARE COORDINATION FOR CHILDREN WITH VARIED VULNERABILITY

The clinic reorganization strategies described in the preceding sections create external links that allow the clinician to identify and address community-level health risk and protective factors (see Box 20-2). The strategies and interactions that are now described address individual- and family-level risk and protective factors.

Box 20-2. Strategies for Organizing and Reengineering the Clinical Practice

- Review community epidemiological data to identify community-level health risk factors and to guide development of targeted health service delivery pathways
- Establish external links to CBOs through an asset mapping process
- Position the practice as a service delivery hub
- Tailor practice-based assessment, education, intervention, and care coordination for vulnerable children

The health supervision guidelines outlined in Bright Futures provide detailed, age-specific recommendations for surveillance, assessment, and intervention.[38] These pediatric clinical services can be organized into four major categories: assessment, education, intervention, and care coordination. Each service delivery component may be tailored to patients with varying levels of vulnerability, which is also known as tiered care. Tailoring assessment, education, intervention, and care coordination to families with varied vulnerability requires adjusting the content (what services are delivered), the context (how services are delivered), and contacts or personnel (who delivers the services) to meet families' needs.

CONTENT OF CARE ASSESSMENT

> Routine screening reveals that Xavier has language delays, a body mass index of >95%, dental caries, and mild anemia. He goes to bed routinely at 11:00 PM, eats fruits and vegetables three times per week, drinks soda daily, watches 3 hours of TV daily, and is exposed to neighborhood violence. The family interview reveals that both parents work and are unaware that there are resources like a library, park, CBO, and community garden in the neighborhood. The family has support through their faith community and several family members living in the area.

Individual assessment and routine screening for diverse problems is important in caring for children. Published guidelines highlight appropriate screening topics and timing for screening.[38] A variety of assessment tools are also available to help define each child's unique resilience and vulnerability. These tools focus on the individual, family, and community context of health development of children (see "Resources" section). For example, the Parents' Evaluation of Developmental Status (PEDS), The Ages and Stages Social and Emotional Scales,[46,47] and the Survey of Wellbeing of Young Children are validated instruments that assess children's social, emotional, and behavioral development. The PEDS uses a series of questions for parents about their concerns in different domains of development. Tools such as the Family Psychosocial Screening instrument[48] are designed to identify individual psychosocial health risk and protective factors, including parental depression, parental drug and alcohol abuse, domestic violence, and available help and support. Recent publications describe specific models for integrating psychosocial screening into the medical home.[49]

The "Core Competency" table highlights a screening tool used by St. John's Well Child and Family Center, a Federally Qualified Health Center in Los Angeles as part of their participation in the multiagency South Los Angeles Child Welfare Initiative. This "trigger tool" is used to screen and stratify at-risk families for assistance with issues such as housing, legal issues, child care, and child development. The key screening questions are on the left and the key partner agency is listed on the right. In clinic, families are screened at each visit, whether for routine well child care or sick visits. When needs are identified, referrals are made through the electronic medical record to a central care coordinator. Each participating agency is able to make referrals. For example, a family with medical issues identified at the housing agency can be linked to the health-care clinic or a child with housing or legal issues identified in the health clinic can be referred to the appropriate partner agency. Monthly case conferences ensure appropriate alignment of support services.

ASSESSMENT OF VULNERABLE CHILDREN

Underserved children should receive screening that focuses on factors associated with the childhood poverty: assessing both the types and impacts of greater exposure to risk factors and assessing availability and access to resources and health services (protective and health-promoting factors). Because health development is so vulnerable to external forces, all children with difficult social circumstances, particularly children from low-income families, should be screened for developmental delay and psychosocial stressors.

Language development is an especially key area to target, as the "Word Gap Study" showed that children from high-income families heard 30 million more words than children from low-income families, which is then tied to disparities in school performance at age 9 or 10.[50] Using clinical judgment alone only detects 30% of children with developmental disabilities[40-52] and many health-care providers neglect to formally screen. These facts help explain why minor developmental delays often are not detected until school entry or beyond.

In addition, a general epidemiologic assessment of the community, as described, will identify community-level risk and protective factors for all children living in the area. During the clinic visit, the provider may assess an individual child's exposure to key community-level risk and protective factors. For example, through the epidemiologic assessment, a provider may have identified that 10% of the children in the community have asthma. With a known high prevalence of asthma and a potential high exposure to environmental pollutants, the provider may

choose to carefully assess children who live in high-risk areas for asthma, thereby targeting those at risk before a major asthma exacerbation. Similarly, with a known high prevalence of obesity, the provider may specifically screen for food insecurity, fruit and vegetable consumption, sweetened beverage consumption, limited safe play areas for children, and other lifestyle behaviors/circumstances that can promote or prevent childhood obesity.

PARENT AND PATIENT EDUCATION

> Xavier's provider understands the multiple risks (poverty, lack of educational opportunity, poor nutritional options, exposure to violence) and protective factors (large united family, strong sense of community and cultural identity, faith community, neighborhood with active CBOs, as well as an active and engaged child and engaged parents) that contribute to Xavier's health. Xavier is referred to early intervention services, the local library, a developmentally focused child care center, local nutrition classes, a community garden, parenting classes, and the dental van. He has his hearing and lead levels tested. His family is given guidance on Xavier's nutrition, physical activity, and reading.

Health visits are recognized as an opportunity for informing parents about their children, with a particular emphasis on prevention. When the clinician is armed with specific knowledge of the patients' experiences and potential health risk and protective factors, education and anticipatory guidance can be tailored to address the impact of those factors, allowing for more targeted and rewarding information exchange and educational intervention. For example, a child raised by a teenage parent in a community with low literacy rates and an overcrowded school system is at risk for language delay. A targeted educational intervention takes advantage of a local library with a free story time class, a clinic-based Reach Out and Read (see "Resources") program, a highly involved and engaged grandparent, and access to an in-depth assessment through an Individual Education Plan (IEP) at the school or regional center. Similarly, understanding the impacts of poverty on the quality of parenting, nutrition, establishing and maintaining routines (e.g., sufficient sleep and play time), and other healthy lifestyle habits can help clinicians intervene in these areas to promote health, prevent chronic illness (e.g., Type 2 diabetes), and promote development.

Recent publications have suggested the use of a "parent–child relational framework" to organize primary health-care services toward health promotion.[53] In a parent–child relational system, the parent mediates the context for child health and development. Emphasis on caregiving is central in a relational model and the health-care intervention is organized and individualized around the child's developmental stages and the parent's concerns.

Employing such targeted and responsive strategies when a problem has been identified can also bolster parent confidence in their child-rearing skills and help parents promote the resilience of their children. Family strengths (engaged siblings, grandparents) should be captured as part of the intervention.[31] Similarly, community assets should be incorporated into promotion of health development. Intervention not only includes clinic-based developmental education but also demonstration (modeling book reading, and referral—local library, "mommy and me" groups, or parenting classes). Positive parenting/discipline classes designed to promote an authoritative parenting style (warm/nurturing but firm approach that is associated with improved psychosocial functioning, child development, and educational outcomes) could be a routine part of the clinical intervention.[54,55] Positive discipline is an example of a class/approach designed to promote this parenting style.[56]

Children diagnosed with or at risk for a developmental disability may be referred to publicly funded intervention programs provided through the federal Individuals with Disabilities Education Act (IDEA). For eligible children, these programs provide a comprehensive multidisciplinary evaluation to identify the needs of children and their families to assist in promoting the child's development. Services and programs under IDEA vary from state to state based on age, risk, and level of potential disability. The National Early Childhood Technical Assistance Center Web site provides details on each state's eligibility requirements and program components (see "Resources").

CARE COORDINATION

> Xavier's anemia improves on iron therapy. The family has not attended a nutrition class, but has stopped by the CBO and will attend the class soon. They are participating in the local community garden and have started growing their own vegetables. He now goes to the local park daily as part of his new routine. He is also going to the library story time once a week and has started developmentally focused child care. His parents read to him daily and he has developed a few more words. They are learning new positive discipline skills from classes and peers at the CBO.

The final component of service for children is care management and coordination. There is an immediate need to have ongoing monitoring and coordination of care for children (particularly vulnerable children) to ensure that they are connected with relevant services and resources in the community. The greater the level of child and family need and more fragmented the delivery system, the greater the need for effective care coordination. Barriers to care coordination include unclear service obligations (who is eligible and who provides services), how information is communicated to and from referral agencies, and how providers are reimbursed.[57] In addition, families often face difficulty with transportation, finances, language barriers, and confusion about services.

The NICHQ Practical Guide to Implementing Office Systems for Anticipatory Guidance can guide the practice in creating internal capacity for this activity (see "Resources"). Bright Futures also has resources for systems change, improving preventive care and implementing quality improvement cycles (e.g., Plan Do Study Act, PDSA).[38] Furthermore, the National Committee for Quality Assurance (NCQA) has developed quality standards, performance measures, and tools to support provision of high-quality health care.[58] The PCMH offers a clinic-based model to facilitate better coordination of care. Many practices are seeking certification from the NCQA or Joint Commission as higher reimbursement may be tied to achieving certain levels of PCMH.

In addition to these clinic-based levels of care coordination, state-level partnerships also exist to facilitate better care management. One program, Help Me Grow, is a cross-sector collaboration in 17 states that seek to identify children at risk for developmental delay and link families to the right program or service for their child.[59] Often integrating state departments of education and health and human services with local agencies, this program has demonstrated significant gains, not only in connecting families to services but also to increasing parental self-empowerment and management. Coordinating care benefits the individual child and family and optimizes use of local and state resources.

CONTEXT OF CARE

Once a child has been identified as being underserved or at risk for developmental delay, obesity, asthma, or having special health-care needs, he or she often requires additional time and attention within the clinical practice. Clinical systems can be modified to create more customized clinical care pathways and tiered care to allow for more effective and efficient implementation of the assessment, education, intervention, and care coordination components that are outlined here. For example, the front desk staff can use different scheduling algorithms to match the intensity of visit to allocated time of an appointment. Similarly, a practice may choose to schedule many of their more complex multiple-needs patients on the same day or afternoon, and alter staffing patterns to allow a nurse and clerk to be responsible for extended care coordination needs. In many regions of the United States, such extended visits can be coded and reimbursed at a higher level of intensity, thereby coupling a more responsive, effective, and efficient delivery strategy with appropriate reimbursement. The child's family may need more frequent visits to allow for medically necessary case management, to assure that they are receiving appropriate developmental services and that the services are having the expected effects. Practices and clinics that care for a number of children in specific school or child-care centers may also set up direct lines of communication with designated health personnel at those institutions.

COORDINATION OF STAFF PROVIDING CARE

It is increasingly recognized that high-quality health care is a team endeavor. In this case, high-quality care team for the child who is at risk for developmental delay or vulnerable by the constellation of risk factors associated with poverty includes the clinicians, nurses, front desk, and care coordination staff. In addition, randomized control trial evidence reveals that for this group of children, clinical outcomes and practice-based efficiency and effectiveness can be improved by adding a developmental specialist (master's level nurse or a developmental psychologist) to the team.[60] For children with special circumstances or multiple vulnerabilities, the clinician often needs to coordinate a multidisciplinary team, including subspecialists and/or social work staff.

CONCLUSION

Children are an inherently vulnerable population. Individual-, family-, and community-level health risk and protective factors influence the health development of children. Traditional medical care is individual and disease focused, largely ignoring the contextual factors that impact health. Modern definitions of health call upon providers to reorganize medical practice to integrate consideration of these factors into clinical care to enhance the future well-being of children and the adults they will become. Moreover, implementation of the Affordable Care Act offers a unique opportunity to transform children's health care, through adoption of Bright Futures as the standard of care, and a shift in focus to prevention and wellness.

- Children's health is the foundation for lifelong health.
- Children's health cannot be understood apart from development and function.
- Social factors are important determinants of health; integrating them into clinical practice is of paramount importance.
- Identifying and bolstering protective factors is as important as mitigating risk factors for poor health.
- Health promotion (rather than disease modification alone) can have important impacts on individual and population health.
- Children are inherently vulnerable, and poor children are particularly at risk for poor health.
- Tailoring clinical practice to care for vulnerable children includes thorough community and individual patient assessments, education, interventions, and coordination of care.

Well Being (Mental Health, Trauma, & Social/ Emotional Support)	Are you concerned about how your child gets along with others? Does your child have issues managing emotions? • Difficulty Expressing Feelings • Sad • Frustrated/Angry • Not Easily Calmed Down • Lonely/Isolated

DISCUSSION QUESTIONS

1. How does a disease-based focus influence how we think about patients and their care?
2. Why may development be used as an indicator of children's health?
3. What influence can a health-care provider have on a child's health development trajectory?
4. What are the challenges to reorganizing a clinical practice to address the contextual factors that influence health?
5. Can you think of examples of health-care providers who successfully address the multiple determinants/ contextual factors that influence health? How have they accomplished this?

RESOURCES

This Web site tracks 10 key indicators of child well-being. http://www.kidscount.org

A Practical Guide to Implementing Office Systems for Anticipatory Guidance http://www.nichq.org

This Web site offers tools addressing development, mental health, vision, hearing, and oral health for use in the office setting. http://www.medicalhomeinfo.org/screening.html

The National Early Childhood Technical Assistance Center supports the national implementation of the early childhood provisions of the Individuals with Disabilities Education Act (IDEA). http://www.nectac.org

Reach Out and Read. http://www.reachoutandread.org

What makes us get sick? Look Upstream: Dr. Rishi Manchanda. http://www.ted.com/talks/rishi_manchanda_what_makes_us_get_sick_look_upstream

Childhood Poverty: Dr. Bert Lubin at TEDxGoldenGatePark. http://tedxtalks.ted.com/video/Childhood-Poverty-Dr-Bert-Lubin

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Chapter 21

Vulnerabilities of Adolescence and Young Adulthood

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Objectives

- Recognize the relationship between adolescent development and vulnerability to poor health outcomes.
- Identify characteristics of uniquely vulnerable adolescent subpopulations.
- Describe variations in adolescent morbidity and mortality in vulnerable subpopulations.
- Review behavioral risk factors that contribute to adolescent vulnerability.
- Describe interventions to decrease risks.
- Identify individual, family, and community protective factors supporting adolescent health and well-being.

INTRODUCTION

Rosa is a 15-year-old girl who comes into the community health clinic with her mother. She has vague abdominal complaints but denies nausea, vomiting, or diarrhea. Her mother shares that they have not come in for regular health care because of concerns about cost and not having legal residency in the United States. They came to the United States from Mexico when Rosa was 7 and live in a small apartment in the inner city with Rosa's aunt and her family. Rosa's father lives in Mexico.

Adolescence is the transition from being a dependent child to an independent adult. Extending from the onset of puberty until the completion of brain development (roughly between the ages of 10 and 26), it is a time of great vulnerability and opportunity. The health-related behaviors and conditions of most noncommunicable diseases—tobacco and alcohol use, diet and exercise habits, and increased weight—often begin in adolescence. In addition, sexually transmitted diseases; human immunodeficiency virus (HIV); and other health issues, for example, those related to early maternity or to exposure to violence, also have serious impacts on the health and development of adolescents, their future adult selves, and future generations. With over 1 billion adolescents worldwide, the importance of this stage of life cannot be overstated. Homelessness, recent immigration, minority status, or Lesbian, Gay, Bisexual or Transgender (LGBT) identification further increase the vulnerabilities of this already vulnerable developmental life stage. This chapter focuses on how health-care providers can identify potential problems, support the maturation process and the development of a positive self-image, and address behaviors that may put youth at risk for poor health outcomes.

ADOLESCENT DEVELOPMENTAL TASKS

In the last two decades, neurobiological research, aided by magnetic resonance imaging, has demonstrated the profound brain growth that occurs during adolescence.[1] The cells of the brain respond to hormonal changes (estrogen, progesterone, testosterone), and are likely influenced by

Table 21-1. Developmental Vulnerabilities and Risks at Different Stages of Adolescence

Stage	Developmental Vulnerabilities	Risks
Early adolescence: (10–13)	Concrete thinking with increasingly independent decision making	Limited ability to consider consequences. Asynchrony between brain and body, i.e., early sexual debut
Middle adolescence: (14–17)	"Hot cognition" executive function/ thinking highly colored by emotion	Height of experimentation, risk taking
Late adolescence: (17–21)	Executive function still maturing, difficulties with prioritization	Increasing autonomy, legal responsibility may result in legal or financial risks
Young adult: (21–26)	Executive function not fully mature until 26+ Expected to function effectively in the adult world	Have moved out of supportive child/ adolescent systems into adult systems that may not be well suited to their needs

environmental factors such as nutrition, education, infection, and parenting. The limbic structures of the brain, associated with socioemotional development, are among the first to experience changes accompanying the onset of puberty, although full maturation does not occur until later in adolescence.[1] The neural connections of the prefrontal cortex, responsible for cognitive development and impulse control, develop more slowly.[1] It is this "asynchronous" development of the brain that may lead to emotional liability, risk taking, and behavioral control issues.

The overall task for the adolescent is to become an autonomous functioning "other" adult, individuated from his or her family. Adolescent psychosocial development generally is described in three stages: early adolescence (10–13 years), middle adolescence (14–17 years), and late adolescence (17–21 years). More recently, late adolescence has been combined with or followed by a fourth stage, young adulthood (18 or 21–26), which is an increasingly studied and referenced developmental stage. Developmental tasks of adolescence include acceptance of sexuality (which does not necessitate being sexually active), developing future life plans, beginning to develop life philosophies, and transitioning to adult roles and responsibilities in young adulthood.

The principal task confronting the family with adolescents is to strike a changing balance between freedom and personal responsibility as adolescents mature and individuate. Although most adolescents are able to navigate these developmental tasks successfully and without lasting social and emotional consequences, for those who do not, the adverse effects can persist well into adulthood (Table 21-1).

EPIDEMIOLOGY AND RISK-TAKING BEHAVIORS

The leading causes of adolescent mortality globally are road injuries, HIV/AIDS, and self-harm. Mortality is higher in boys than in girls and higher in older adolescents than in younger adolescents. These deaths are closely related to adolescent risk taking. Risk-taking behaviors are defined as those potentially harmful to the initiator or others that exceed normal behavior for that developmental phase.

The Youth Risk Behavior Surveillance (YRBS) System monitors six categories of priority health-risk behaviors among youth and young adults in the United States (http://www.cdc.gov/HealthyYouth/yrbs/index.htm).[2] Although high-risk behaviors among high school students have decreased since 1991, the 2013 YRBS report indicates that adolescents continue to engage in behaviors that place them at risk for the leading causes of morbidity and mortality. Seventy-two percent of all deaths in 2011 among persons aged 10–24 in the United States continue to be related to behaviors that contribute to unintentional injuries and violence: motor vehicle accidents (26%), other unintentional injuries (17%), homicide (16%), and suicide (13%).[3]

For example, in the United States, vehicular accidents remain the leading cause of mortality and morbidity among young people. The 2013 YRBS data indicate that teens engaged in high-risk behaviors that are associated with motor vehicle accidents: 41% of adolescents texted or e-mailed while driving, while 35% had consumed alcohol in the past month (10% drank prior to or while driving and 21% rode with a driver who had been drinking) and 23% had used marijuana in the past month.

Risk-taking behaviors for suicide and sexually transmitted diseases are also common in adolescents. Alcohol and substance use along with access to a weapon are significantly associated with both homicide and suicide. In 2013, 30% of teens reported feeling sad or hopeless at a level consistent with clinical depression. Seventeen percent seriously considered suicide, with 14% making a plan and 8% actually attempting suicide in the past 12 months.[3] In the same year, 18% of high school students had carried a weapon in the past month, with 6% reporting carrying a gun. Among sexually active high school students in the United States, the 2013 YRBS survey found that 15% of adolescents had had intercourse with four or more partners and 59% had used condoms during their previous intercourse. World Health Organization (WHO) data indicate that globally, at least half of 15-year-olds who are sexually active report using condoms the last time that they had sex.[3]

FRAMEWORK FOR DEFINING VULNERABLE ADOLESCENT SUBPOPULATIONS

> After Rosa shares that she is very concerned about her school performance, she is happy to hear that she can be referred to a teen case manager. The case manager can work with Rosa to enroll her in a tutoring program to improve her English skills.

Although any adolescent may engage in behaviors that can compromise their health, certain individual, family, and community characteristics can result in greater vulnerability in adolescence. Contextual factors such as the physical environment, the social environment, and the availability and access to health and social services have been proposed as a framework for assessing urban adolescent vulnerability worldwide.[4]

Physical environments associated with a higher prevalence of adolescent pregnancy and sexually transmitted infections include communities or neighborhoods with high levels disorganization, physical disorder (run-down buildings, broken windows, trash, and graffiti) and poverty. In addition, exposure to adults who have lower levels of education, lower income, and higher unemployment is more likely in these neighborhoods.[5] Lack of recreational facilities, youth-oriented organizations, and positive alternatives for activities during out-of-school time are correlated with poorer reproductive and sexual health outcomes for girls and young women and involvement in alcohol and drug use and violence for boys and young men.[6]

Social environments include the home and family as well as the broader social environments of school and community.[7] Unstable households where there is a lack of parental engagement and monitoring, limited parental presence in the home (whether due to the need to work long hours or multiple jobs to support the family, incarceration, parental drug or alcohol use, or other issues that limit parental presence and engagement), poor communication patterns, and domestic violence or abuse are associated with increased risk behaviors and poorer health outcomes in youth. Family rejection and lack of familial and social support for youth who are gay, lesbian, bisexual, or transgender (sexual minority youth) are associated with higher sexual risk, mental health, and substance use problems.[8] Lack of academic goals and low levels of school engagement are associated with earlier sexual debut, early childbearing, and substance involvement.[9] Family norms and expectations, perceived peer norms, and community norms all influence adolescent decision making when it comes to risky behaviors.

Problems in school are problems in themselves, jeopardizing an adolescent's future employment possibilities, for example. School phobias, truancy, academic failure, fights, poor concentration, learning disabilities, and school dropout or suspension may be indications of other underlying troubles. Early identification and intervention of school problems may prevent progression to other adolescent risk behaviors.[10]

ACCESS TO CARE AND CONFIDENTIALITY

As a whole, adolescents are among the most underserved populations worldwide. Routine checkups for adolescents are rare in both developed and developing countries alike.[11,12] While some youth may be reached in traditional health clinic settings, nearly half of those surveyed by the WHO global consultation indicated a preference for school-based health centers. Any facility-based care may not reach the most vulnerable adolescents, including homeless, runaway, and immigrant/migrant youth.[13]

Lack of confidentiality, real and perceived, can be a major barrier to care.[14] Even with symptoms, a significant number of adolescents forego health care because of concerns over confidentiality. Studies indicate that if mandatory reporting for reproductive health services were instituted, 60% of adolescents would delay or discontinue seeking reproductive health-care services. Low-income and uninsured adolescents are even less likely to get confidential care.[15]

Key tasks for health-care providers working with adolescents lie in navigating the legal and political landscapes in which privacy and confidential care are not protected. Accessible, convenient care across a spectrum of settings from school-based health centers and community clinics to urgent care and emergency rooms may be venues for adolescents seeking care. Regardless of the setting, it is incumbent on those working with adolescents to address the social and behavioral factors that contribute most significantly to their health status.[16]

Although laws vary, federal and most state regulations in the United States carry exceptions to the requirement for parental consent prior to providing care to an adolescent for reproductive health, mental health, substance abuse, and emergency situations. Adolescents may consent for their own care if they are pregnant, parenting (in some, but not all, states), married, or emancipated minors.[14]

SPECIFIC SUBPOPULATIONS OF AT-RISK YOUTH

Specific subpopulations of youth are at risk for experiencing greater challenges and are more vulnerable to poorer outcomes as they move through adolescence and into adulthood. Particularly vulnerable youth populations include immigrant, poor rural and urban, educationally disadvantaged, homeless, runaway, and sexual, racial, and ethnic minority youth.

Youth of Color: Racism as a Source of Vulnerability

Youth of color, particularly African-American and Latino adolescents, face additional vulnerabilities owing to structural inequities and institutionalized racism. They

are likely to be over-criminalized, over-policed, and consequently over-represented in incarceration systems.[17] Experiences of racism and discrimination result in lowered self-esteem, increased rates of depression, and poorer educational outcomes.[18,19] Institutionalized racism occurs even in clinical settings, as African-American and Latino youth are disproportionally diagnosed with Conduct Disorder.[20] Fifty plus years after the Civil Rights act, African-American youth are still likely to live in segregated neighborhoods and are more likely to attend segregated public schools now than they were 40 years ago.[21,22]

Immigrant Youth

Immigrant youth are vulnerable to discrimination, and if they struggle with English proficiency they may be educationally and vocationally vulnerable as well. Immigrant youth are often faced with conflicting pressures of acculturation versus maintenance of a sense of ethnic and cultural heritage. Data are conflicting in the directionality of risk and acculturation. Immigrant youth and children of immigrants are most vulnerable when they or their parents lack legal residency. In most states, they lack access to jobs, financial aid for school, and may face difficulties obtaining health-care coverage. They are at risk for multiple vulnerabilities including neglect, foster system placement, or homelessness if their parents are deported.

Youth in the Foster Care System

There are approximately 500,000 children in the foster care system in the United States, with adolescents making up approximately 45% of the foster care population. About half of these children and youth are in nonrelative foster home, 28% are fostered by relatives (kinship care), and 15% live in institutions and group homes.[23] Children and youth in foster care have higher rates of physical, developmental, dental, and behavioral health problems than any other group of American youth. The heightened vulnerability of youth in foster care is attributable to the familial, social, and environmental contexts that resulted in their removal from their home (abuse, neglect, and family dysfunction) and their experiences once in a system that often provides suboptimal environments in terms of safety, stability, consistency, and support-essential assets for developing adolescents.

The instability, impermanence, and fragmentation of home, community, school, and health care for youth in foster care creates an environment that mediates against healthy adolescent growth and development.[24,25] A meta-analysis of research evaluating the impact of intervention programs for foster-care families on the health and mental health outcomes of foster youth showed that effective programs had some common characteristics, including (1) a focus on enhancing individual strengths and reducing specific risk behaviors, (2) a developmentally sensitive and appropriate approach, and (3) a base in the mediating effect of parenting on the impact of adversity on outcomes. The only adolescent-focused intervention found to be effective was a multicomponent program placing foster youth in an individual home where foster caregivers were intensively trained, supervised, and supported to provide mentoring, supervision, and consistent limit setting.[25] The issues of permanence, monitoring and support for both youth and foster caregivers, and continued support for foster youth into young adulthood have emerged as key policy concerns.

The role of health-care providers in reducing the vulnerability of foster youth includes (1) provision of a medical home for youth in foster care, (2) collaboration with child welfare workers to ensure adequate, ongoing health and mental health care, (3) a working knowledge of state programs to provide health coverage to youth and young adults in and aging out of the foster-care system, (4) an understanding of the health needs of and resources for foster youth, and (5) engagement in transition planning for the ongoing care of youth as they age out of the foster-care system.[26] (See Healthy Foster Care America Web site: http://www.aap.org/fostercare for tools and resources.)

Incarcerated Youth

While the rate of juvenile detention has declined over the past 15 years, over 54,000 young people were detained in residential facilities in 2013,[27]and up to an additional 10,000 adolescents are housed in adult jails and prisons on any given night.[28] Young men and youth of color, particularly African-American adolescents and young adults (AYA), are over-represented in the juvenile justice system. African-American, Latino, and Native-American youth are more likely to be detained, to spend more time in detention, to be adjudicated to out-of-home placement, and to be committed to an adult facility than are White youth.[29]

The impact of juvenile incarceration is profound. Recidivism rates are high, and up to one-third of incarcerated youth will return to jail or prison in young adulthood. Rates of reoffending vary by the nature of the crime, with individuals who were charged with property offences the least likely to reoffend and those with violent and drug offences the most likely.[30] Incarceration compounds the vulnerability of these already vulnerable youth, resulting in a significant impact on income for up to 10 years post-release, which, in turn, affects their mental well-being, physical health, social attachments, and life expectancy.[31] Preventing youth incarceration or recidivism is important for public and individual health (see Chapter 27).

Early identification and linkage into evidence-based family interventions such as Functional Family Therapy (see http://www.childtrends.org/?programs=functional-family-therapy) and Multisystemic Therapy (see http://www.childtrends.org/?programs=multisystemic-therapy)

and/or individual interventions such as Insiders Juvenile Crime Prevention (see http://www.childtrends.org/?programs=the-insiders-juvenile-crime-prevention-program), a "Scared Straight"-style program, exposing youth to the realities of life in prison and Multidimensional Treatment Foster Care (see http://www.childtrends.org/?programs=multidimensional-treatment-foster-care-mtfc) have been shown to have an impact on recidivism and the reincarceration of juvenile offenders in young adulthood.

Gang-Involved Youth

Gang violence accounted for 20% of homicides in the United States from 2002 to 2008.[32] History of incarcerated relatives, acquaintances, and neighborhood exposure to drugs and crime may represent risk factors for gang involvement.[33] Participation in gang activity and living in gang "war zones" put youth at exceptionally high risk for violent injury and death. In addition to death and injury, gang involvement puts youth at high risk of criminal acts, incarceration, substance abuse, and early sexual debut. Gang involvement is further associated with economic hardship and family problems in adulthood. Youth with high coping skills and more parental monitoring have been shown to have lower rates of gang involvement.

The ability and willingness of AYA to leave a gang depends on the length of time of their involvement and the strength of the gang in their area.[34] Successful interventions mitigate the economic and social pushes and pulls of the gang lifestyle. Such interventions include motivational interviewing, referrals to employment assistance, vocational training, remedial/alternative education assistance, counseling, substance abuse services, and mentoring. Evidence-based gang and violence programs such as Gang Resistance Education and Training (G.R.E.A.T.) are available through national partner organizations such as Boys and Girls Clubs of America.[35] Because past or present gang affiliation is often readily identifiable through tattoos on the face, neck, forearms, hands, and other easily viewed parts of the body, tattoo-removal services have emerged in recent years as an important intervention to help youth escape gang involvement.[36]

Youth with Chronic Conditions and Disabilities

Obesity

The prevalence of obesity in US children and adolescents in 2010 was 16.9%, with the prevalence of overweight at 31.8%, both of which were unchanged from 2007 to 2009 levels.[37] There are significant differences in obesity prevalence by race/ethnicity with increased obesity in Hispanic and non-Hispanic black children and adolescents compared with non-Hispanic white children and adolescents. The lifelong risk factors for overweight and obese children and adolescents are well known and include cardiovascular risks, increased health-care costs, and premature death. Extremely obese children and adolescents are also likely to be obese during adulthood; obese adults are at increased risk for stroke and many chronic diseases, including coronary heart disease, hypertension, type 2 diabetes, and certain types of cancer.[38]

Reports from the Centers for Disease Control and Prevention (CDC)'s National Center for Health Statistics (NCHS) indicate that socioeconomic status is relevant to obesity in adolescents.[39] Although most obese children and adolescents are not low income (below 130% of the poverty level), low-income children and adolescents are more likely to be obese than their higher-income counterparts. Children and adolescents in households where the head of the household had a college degree are also less likely to be obese compared with those living in households where the household head has less education, but the relationship is not consistent across race and ethnicity groups.

Adolescents who experience food insecurity, that is, lack of resources to obtain adequate nutritional intake, often maintain a substantial portion of their dietary intake on "junk" (high caloric) foods that can lead to obesity, for example, excessive soda beverages, foods high in carbohydrates, fried foods, and snacks, with minimal intake of recommended portions of protein, fruits, and vegetables. Clinicians working with adolescents need to obtain dietary histories on all patients as well as body mass index measurements.[40] Questions about usual sources of food and identifying food insecurity can be included in the modified HEEADSSS screen (see "Core Competency"). When food insecurity and/or obesity are identified, clinicians should attempt to engage the adolescent in teen-friendly weight management programs as well as programs that can provide adequate resources to address food insecurity and weight management.[41,42] Community-based programs such as Boys and Girls Clubs are excellent resources to address these issues and engage the teens in creative nutritional education programs.

There are few public health and dietary education reports that address disparate health needs of specific populations. One study reported that the diets of Hispanic children, regardless of the level of acculturation and food insecurity, were less nutritious than the national average for children in the United States, and do not contain adequate quantities of healthful foods such as fruits and vegetables, suggesting a need for qualitative research into the underlying communication and acculturation processes and how these affect diet and nutrition.[43] Another study on food insecurity found that interventions to improve food-insecure adolescents' eating behaviors may benefit from supporting mothers' use of health-promoting parenting practices.[44]

Adolescents with disabilities

Youth with developmental and/or intellectual disabilities encounter challenges that may increase their

vulnerabilities and impair their access to health care during adolescence. The Americans with Disabilities Act requires health-care professionals to ensure access to health care (Developmental Disabilities Assistance and Bill of Rights Act of 2000 http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/Index.aspx). These adolescents and their families or caregivers have special needs that require, among other skills, particular knowledge and skills for examination room etiquette, effective communication, knowledge of resources, and skills with working in interdisciplinary teams (see Chapter 42).[45]

Adolescents with disabilities also need access to sexuality education and medical care that addresses their sexual health needs. As with all adolescents, these teens need to be able to have confidential and private discussions with providers that address their gender and sexual identity, sexuality, prevention of sexually transmitted infections, and pregnancy. The Office of Developmental Primary Care (http://odpc.ucsf.edu.) offers many resources for the care of adolescents with disabilities. Of particular concern for parents and caregivers of youth with disabilities is their increased risk of vulnerability to physical and sexual violence, neglect, and emotional abuse. Vulnerability to abuse is increased for those youth whose disability leads to heightened dependency on others, particularly those with intellectual disability, and for those with communication difficulties. With mild developmental impairments, victimization can be related to the need to "fit in" and be like their peers. Although families frequently express concerns about the risks of stranger abuse, family and caregivers more frequently perpetrate abuse. Although findings related to the prevalence and risk of abuse varies between studies, a recent meta-analysis of international data shows a consistent finding of a higher prevalence and risk for abuse among youth with disabilities than for their peers without disabilities.[46]

Chronic conditions

Management of chronic conditions, for example, asthma and diabetes, can be especially challenging for vulnerable youth with minimal resources and/or family supports. Throughout earlier childhood, parents and caregivers regularly make treatment decisions. During the transitions through adolescence, youth need to become more involved in taking control of their chronic illness management. However, there have been few studies that look at how these decisions are made during the childhood years.[47]

VULNERABILITIES IN SEXUAL HEALTH OUTCOMES

> After reviewing confidentiality with an interpreter, Rosa's mother goes to the waiting room. Rosa reveals that she has had both one male sexual partner and one female partner. Her last menstrual period was 2 months ago.

Development of one's sexual identity is a normative and expected process that occurs during adolescence and young adulthood. The abilities to engage in romantic relationships and experience intimacy are positive aspects of sexual identity. However, there are risks associated with sexual behaviors, including sexually transmitted infection and unintended pregnancy. These risks are often intensified during adolescence and young adulthood when sexual activity is often initiated without an accurate understanding of reproduction, contraception, or the transmission of infection.[48]

In the United States, early sexual debut (sexual activity prior to the age of 14) is uncommon. Fewer than 8% of adolescents have had sex by their 14th birthday. However, the percentage of adolescents who have had sex increases after the age of 15, and by 12th grade 49% of youth have been sexually active in the past 3 months.[3] By the age of 20, 74% of adolescents, both male and female, have initiated sexual activity.[49]

The percentage of young adolescents, ages 13–15 years, who have had sex varies greatly by specific country, from approximately 70%(males in Samoa and females in Greenland) to less than 1% (both males and females in Indonesia).[2] However, the overall rate of sexual activity among adolescents is similar in most high-income countries, and not dissimilar to those living in low- and middle-income countries (LMICs): by the age of 18, 60% of females in the United States and sub-Saharan Africa have had sex.[49,50] In LMICs, sexual activity usually occurs within the context of marriage, with early sexual debut associated with early marriage. Globally, 34% of girls are married before the age of 18 years, and 11% are married before the age of 15.[51] In many LMICs, however, the decreasing age of puberty and the increasing age of marriage are resulting in an increase in premarital sexual activity among adolescents.[52]

Sexual coercion and exploitation are common in adolescents. In the United States, about 7% of adolescents, 11% of girls, and 4% of boys report sexual exploitation.[3] Sexual coercion is more likely among younger adolescents, with 50% of US girls who had sex by the age of 11 and 23% of those who had sex by the age of 12 reporting that their first sexual experience was not consensual.[49] Perpetrators of sexual coercion include partners (dating violence), family members (incest), and strangers. Sexual coercion is common in other countries as well. In Malawi, 14% of females aged 15–19 reported their first sexual encounter was forced.[53] A study of Chinese high school students found that 41% of females and 30% of males had experienced sexual coercion.[54]

SEXUALLY TRANSMITTED INFECTIONS

Sexually transmitted infections (STIs) challenge public health systems in the United States and worldwide, cause

significant morbidity and economic burden, and disproportionately affect AYA. The estimated annual incidence of STIs in the United States is nearly 20 million, with 50% occurring in youth ages 15–24, although they comprise only 25% of the sexually active population.[55] The most prevalent STI is human papilloma virus (HPV), followed by chlamydia and trichomoniasis.[55] While condoms remain the most commonly used method of contraception among US AYA and provide the most effective protection against STIs, 41% of sexually active adolescents reported not using a condom at last intercourse in 2013.[3]

HUMAN IMMUNODEFICIENCY VIRUS

Of particular concern is infection with the HIV. HIV is now the second leading cause of mortality among the world's adolescents.[2] Ninety percent of these deaths occur in sub-Saharan Africa, where one out of every six adolescent deaths is due to HIV.[2] Among AYA ages 15–24, the global HIV prevalence is 0.4% (about half that of total global prevalence) or more than 2 million AYA living with HIV.[2] Countries in sub-Saharan Africa have been particularly devastated by the HIV epidemic, and again, youth are disproportionately affected. For example, the HIV prevalence rate among AYA is 11% in Lesotho and Swaziland, and 9% in South Africa.[51] In much of the world, women are equally, and in some countries more, affected than men. Globally, girls and women aged 15–24 have twice the HIV infection rates as their male counterparts.[56]

In 2010, 26% of new HIV infections in the United States occurred in youth ages 13–24, although they represented only 17% of the population.[57] At particular risk are AYA males who have sex with other males and minority youth.[57] An estimated 39,000 youth are living with HIV in the United States as of 2010. About 28,000 of those infected are AYA boys/men who acquired the infection from sex with other men; 13% were infected perinatally. Approximately 11,000 AYA girls are HIV infected, 56% as a result of heterosexual contact, and the remainder perinatally infected.[57]

PREGNANCY AND CONTRACEPTION

Pregnancy in adolescents, both married and single, is common throughout the world, particularly in LMICs. An estimated 16 million girls aged 15–19 give birth each year, accounting for 11% of all births. Approximately 95% of these births occur in the poorest countries.[58] Most adolescent pregnancies occur within the context of marriage, with nearly 100% of pregnant adolescents married in Asia and Northern Africa, yet only 70% of pregnant adolescents are married in sub-Saharan Africa.[59]

In the United States, teen pregnancies have been declining, but still remain higher than the rates found in other developed countries. In addition, significant disparities in teen pregnancy rates exist among poor and minority AYA. Black, Hispanic/Latino, American-Indian/Alaska Native and socioeconomically disadvantaged youth, particularly those in foster care and with histories of exposure to the juvenile delinquent system, experience the highest rates of teen pregnancy and childbirth.

Adolescent pregnancies can have a number of deleterious effects on both the mother and her child. Very young mothers are at high risk of perinatal complications, from preterm birth to preeclampsia. In low-resource countries, where a lack of health-care facilities and providers and a high prevalence of anemia and malaria infection confer additional risks for adverse perinatal outcomes, studies document an increased risk of perinatal complications including an increased risk of preterm labor, preterm delivery, and neonatal deaths among pregnant adolescents.[60,61] According to research conducted by the WHO's Making Pregnancy Safer program, pregnant young adolescents (younger than 16 years) have a four times higher risk of maternal death than older women, and a 50% higher death rate among their infants.[62] The health consequences for adolescents and their children are less severe in developed countries with a lower prevalence of infectious diseases and higher access to medical care.

In addition to the risk of poor health outcomes, adolescent pregnancy has a negative impact on social and economic status of mothers and their children. Adolescent mothers are more likely to drop out of school while pregnant and not return; unmarried pregnant adolescents also risk rejection by their family and partner, and, lacking education, have difficulty obtaining or maintaining employment. The children of teenage mothers bear the largest burden of teenage pregnancy. They are at higher risk for long-term problems in many major areas of life, including school failure, incarceration poverty, child abuse, physical or mental illness, and becoming teen mothers themselves.

Rosa was relieved to hear that her pregnancy test and the STI screening tests were negative. She decides to have an Intrauterine Device (IUD), a long-acting reversible contraceptive method, placed as long as her mother is not informed about this. She will ask Juan to use condoms and she is pleased to hear that her boyfriend can also be seen in a teen-friendly clinic.

Source: See http://www.acog.org/About-ACOG/ACOG-Departments/Long-Acting-Reversible-Contraception/LARC-Clinical-Resources

CONTRACEPTION

Prevention of early pregnancies and of STIs is important for teens themselves, their futures, and their children. Use of contraceptives, especially condoms, is a potent preventative strategy. Contraceptive use in LMICs is low

compared to developed countries. Sub-Saharan Africa has the lowest contraceptive prevalence rate among the major regions of the world, and contraceptive uptake among youth 15–19 years of age is poor. Even among married adolescent girls in sub-Saharan Africa who wish to avoid a pregnancy within the next 2 years, 67% are using no contraception and 12% are using a traditional method (e.g., periodic abstinence, withdrawal, herbal remedies).[63] Contraceptive use by AYA has increased in recent years in the United States, and among older adolescents, the use of long-acting reversible contraceptive (LARC) methods has increased threefold.[64] Use of these more reliable forms of contraception and increased use of contraception in adolescents in general underlie the dramatically declining rates of adolescent pregnancies in the United States. Nevertheless, many AYA do not use contraception or use it inconsistently. Among the reasons for non-use of contraception by AYA worldwide are the belief that one "cannot" get pregnant, lack of access to and education about reliable methods, or desiring ("not minding") if pregnancy occurs.[65]

An unintended pregnancy in AYA may result in therapeutic abortion. In LMICs, access to abortion is often limited or illegal, leading to an epidemic of unsafe abortion. Of the 21.6 million unsafe abortions that occur each year in the world and in Africa, 15% and 22%, respectively, are in adolescent females ages 15–19.[66] Lack of access to modern contraceptive methods and safe abortion further increase the vulnerability of AYA in LMICs. Recent data indicate that the adolescent abortion rate in the United States is the lowest it has been because abortions were legalized, again, secondary to increased contraceptive use.[67]

VIOLENCE

> Rosa also reveals that her current boyfriend, Juan, age 17, has pressured her to have intercourse. She is also concerned because she thinks he is in a gang and worried that information about her relationship with him could result in her family being deported back to Mexico.

Whether violence at the hands of romantic partners, gangs, family, or war, it remains a significant and disproportionate cause of both morbidity and mortality in adolescence, particularly for minority youth. Homicide is the second leading cause of adolescent mortality in the United States and the fifth most common reason worldwide. In the United States, homicide disproportionately affects minority youth and is the leading cause of death for adolescent African Americans.

Identified risks for violent behaviors include substance use and abuse, aggression, delinquency, academic failure, poverty, family conflict, gang membership, and living in a neighborhood with a high prevalence of crime and drug use.[68] Violence-related behaviors in US adolescents tracked by the YRBS include weapon carrying, physical fighting, experiencing threats, injuries, feeling unsafe at school, bullying, and dating violence, including coercive sexual activity and sexual assault.

Dating violence is also a significant problem for adolescents (see Chapter 35). Nationwide, 10.3% of high school students reported being hit, slapped, or physically injured by an intimate partner. Girls were significantly more likely to have been forced to have intercourse than boys; 10.5% versus 4.2%, respectively.[3] Unhealthy and abusive relationships during adolescence predict abusive relationships in adulthood as well: one in five women and one in seven men who ever experienced intimate partner violence first experienced these partner dynamics between 11 and 17 years old.[69]

> The teen case manager will talk to Rosa about strategies and resources to keep her safe and effectively address issues of bullying and dating violence.
>
> Resources: Break the Cycle: Empowering Youth to End Domestic Violence: http://www.breakthecycle.org

VULNERABILITIES OF SEXUAL MINORITY YOUTH

> Jared is a 15-year-old homeless boy who comes into clinic complaining of a sore throat. Jared ran away from home after his parents discovered he was having sex with men. He has been living on the street. He is exchanging sex with men for drugs and money and is currently being treated for rectal gonorrhea. His syphilis screen was negative, and he declines HIV serology despite counseling regarding his risk. He has been smoking marijuana daily since he has been on the street, smokes a half pack of cigarettes daily, and states that he has "tried just about everything else you can get high on, but no needles … they scare me!"

Over the past two decades, the development of a same-sex sexual orientation and self-identification as lesbian, gay, or bisexual has become a developmental process of adolescence.[70] For many of these youth, this is a time of great turmoil, not wanting to be "different," or fearing rejection by parents, friends, and peers. The adolescent may experiment with opposite-sex sexual activity as well as exploring their sexuality with same-sex partners. Gay and lesbian youth have a 50% chance of being rejected by their families and often are ejected from their homes, making up 42% of homeless youth and 28% of school dropouts.[71] These youth are frequent targets for verbal harassment and physical abuse, both in school and on

the streets.[71] Because of social isolation, familial rejection, and dysfunctional coping mechanisms, they are at significant risk for substance abuse, STIs (including HIV), depression, and suicide.[72]

MENTAL HEALTH

> When asked about his mood or thoughts of harming himself, Jared admits that he has had some thoughts of suicide, but does not have a definite plan. This is confirmed by the PHQ-A: http://www.uacap.org/uploads/3/2/5/0/3250432/phq-a.pdf; Scoring instructions: http://www.cappcny.org/home/documents/phq 9 teens scoring.pdf.

Although mood swings, particularly among early adolescents, may be normative, depression is a common and often under-recognized health problem. Depression is the greatest cause of illness and disability in adolescents, with suicide the third most common cause of death of youth worldwide.[2] The 2013 YRBS found that 16% of high school students in the United States had considered suicide in the past year and 13% of high school students seriously considered making a suicide attempt, with 8% actually making an attempt.[73] Suicidal ideation is reported at more than twice the above rate for sexual minority youth.[71] Firearms account for 81% of suicide deaths among adolescents ages 15–19. There are significant increases in suicide rates in families with a history of suicide, affective disorders, alcohol and drug abuse, physical or sexual abuse, and adolescents with prior attempts. Girls make more suicide attempts, and boys complete more suicides. Clues to impending suicide attempts include giving away valued possessions, saying good-bye, accident proneness, poor self-image, deterioration of personal hygiene, increased isolation, and talk about attempting suicide. Studies indicate that nearly 90% of suicidal youth had primary care visits during the prior 12 months of a suicide attempt, often for vague somatic complaints.[74]

Although the clinical presentation of depression in adolescents may be similar to that of adults, there are some differences that can be attributed to the physical, cognitive, social, and emotional developmental stages adolescence. There are more eating and sleep disorders, aggressive behaviors, delinquency, difficulties concentrating, school problems, sexual partners, daredevil behaviors, pregnancies, and issues with alcohol and drug use. Parents often need assistance in differentiating these behaviors from normal adolescent behavior and mood swings. Adolescent depression frequently results from changes or personal loss including breakup with a partner, recent moves or a change in schools, and family dysfunctions or breakup. Depression and a past history of alcohol use are predictors of suicidal ideation and attempts.[75]

In addition to depression and suicide, other mental illnesses begin to become evident during adolescence. Worldwide, schizophrenia will affect 1 out of 100 people. The onset is usually during the adolescent and young adult years. It is unusual to identify a new diagnosis of schizophrenia in those younger than 12 years or older than 40 years.[76] One percent to 3% of adolescents may be affected with bipolar disorder (BD) and may begin to have symptoms of mood dysfunction, particularly in adolescents with a family history of BD.[77]

SUBSTANCE USE AND ABUSE

Initiation of alcohol and tobacco use often begins in adolescence. Indeed, adults who develop addiction usually began using during adolescence and the earlier age of use predicts greater severity and morbidity. Three-fourths of adolescents surveyed in US high schools report having used addictive substances including tobacco, alcohol, and marijuana, and close to half report being current users of these substances.[78] Factors that increase the risk of progression from experimentation to a substance use problem are multifaceted and dynamic. They include a family history of alcoholism, authoritarian or permissive parenting, lack of supervision, family conflict, easy availability of drugs and alcohol, cultural or religious sanction or acceptance of use, aggressive temperament, low self-esteem, substance using peer group, poor academic performance, and lack of connectedness with school or learning.[79] In addition to being the "gateway" to adult use and abuse, adolescents with substance use problems are at significantly increased risk for depression, academic failure, impaired family and peer relationships, and ongoing cognitive and psychological impairment. Substance use also is a significant contributor to the leading cause of death for adolescents worldwide and in the United States: motor vehicle accidents.

HOMELESS AND STREET YOUTH

While estimates vary according to inclusion criteria, between 1.7 and 2 million youth have run away or are homeless in the United States, with a median age of 14–16 years for both boys and girls.[80] Globally, approximately 150 million youth are considered street children.[81] Homeless youth include those living on the street, shelters, in foster care, or other nonfamily environments. Causes of homelessness among youth in the United States tend to fall into three categories: family problems, economic problems, and residential instability. The majority of youth who leave home report significant family stress and disruption; physical, sexual, and emotional abuse; and neglect. Most homeless youth report that they were either being told by their families to leave or that their

families knew they were leaving and did not care.[82] In LMIC, additional factors contributing to youth homelessness include poverty, war, and violence.[81] Youth in foster care and LGBTQ youth are more likely to be homeless.[83] Approximately 10% of street and shelter female youth are currently pregnant.[84]

An estimated 17 million children and adolescents have lost one or both parents to AIDS since the beginning of the HIV epidemic; the vast majority (90%) of these children live in sub-Saharan Africa.[85] HIV orphans are particularly vulnerable to poverty, malnutrition, property loss, and interrupted education. Many become heads of household for younger siblings, while others are forced onto the streets. Female orphans are more likely to initiate sexual activity early and, if not already perinatally infected with HIV from their mothers, are at higher risk than nonorphans for HIV acquisition.[86]

Medical problems of homeless youth are both a cause and consequence of their homelessness. Homeless youth are at high risk for injuries, physical abuse, sexual exploitation, suicide, and homicide.[83] They have higher rates of substance use and mental illness. A staggering 23–67% of homeless teens report having attempted suicide once.[83] Survival sex and prostitution, with subsequent high rates of STIs; unintended pregnancy; HIV infection; and substance use are common in homeless youth of both genders. Accessing health care is difficult for homeless youth. Some studies indicate that as many as 50% of street youth do not have a regular source of health care, 25% reported serious health problems, and many use emergency departments to meet their health-care needs. Care is often not integrated among agencies, and homeless teens often feel isolated and have fears with regard to receiving health care.[83]

> After meeting with an outreach worker from a multiservice homeless teen center, Jared agrees to go to the center for housing and other resources.
>
> (Sample Resource Larkin Street Youth Services: http://www.larkinstreetyouth.org.)

SOLUTIONS AND INTERVENTIONS

THE PSYCHOSOCIAL ASSESSMENT

Psychosocial assessment is crucial to any adolescent intervention. There are several well-established approaches for conducting adolescent psychosocial assessments. Asking open-ended questions at health maintenance visits pertinent to each area can identify red flags requiring further assessment, as well as referral for care if necessary. It is important to use a strength-based approach in conducting psychosocial assessments (see sample HEADSSS and SSHADESS assessments: http://www.modernmedicine.com/tag/heeadsss-30-and-sshadess). Every adolescent health visit is an opportunity to update a psychosocial assessment.

Because school is the "work" of adolescence, school failure can be an important early indicator of adolescent risks. Therefore, it is particularly important to assess school performance at every regular health maintenance visit. The school physical is an opportunity for a complete and comprehensive physical examination as well as family and psychosocial histories. Providers should be aware of resources in the schools and assistance for children with developmental, mental, and learning disabilities.

SUPPORT FOR PARENTS

Parenting adolescents can be stressful for many families, and health-care providers can offer anticipatory guidance to facilitate healthy outcomes. Prior to the onset of puberty, providers must clearly lay the groundwork for visits during the adolescent years. Clinicians must inform parents and children that issues will be discussed individually and confidentially, except in life-threatening situations, and that adolescents may be examined without the parents present.[87] Providing parents with written patient education materials can be helpful (see CDC Positive Parenting Practices: http://www.cdc.gov/healthyyouth/protective/positiveparenting/index.htm). Assessing for family conflict and addressing family difficulties play an important role in the prevention of high-risk behaviors. Several studies confirm that the following can be "protective" factors for adolescents, regardless of race, class, or gender: an authoritative parenting style with consistent limit setting (versus authoritarian or permissive styles); a sense of connectedness with one caring adult; involvement with parents; a positive body image; participation in extracurricular supervised activities; non-substance using peer group; and strong school affiliation.[88]

LGBTQ FAMILY ACCEPTANCE

In contrast to the high levels of depression, suicide, and risky behaviors of LGBTQ youth facing familial rejection, high levels of familial acceptance result in higher self-esteem and improved health.[8] Health-care providers can use several existing screening tools and culturally appropriate workbooks to help promote acceptance, reunite families, and reduce long-term negative consequences (see Family Acceptance Project Providers Guide: http://familyproject.sfsu.edu/assessment; SAMHSA A Practitioner's Resource Guide: Helping Families to Support Their LGBT Children: http://store.samhsa.gov/shin/content//PEP14-LGBTKIDS/PEP14-LGBTKIDS.pdf).[56]

CONNECTING WITH COMMUNITY RESOURCES

For the many adolescents living without their families, health-care providers can offer a different set of solutions. Connecting AYAs with available local resources including outreach workers, case managers, social workers, youth-oriented school and work programs, and AYA-specific health-care services provides opportunities to form supportive healthy relationships with adults, successfully navigate social and educational challenges, and can mitigate risk taking.

ADDRESSING AYA SEXUAL ACTIVITY

Risks of early-onset sexual behavior should be objectively discussed, with assurances of confidentiality, during late childhood and early adolescent visits. Risk reduction and sexual health are areas to focus on throughout adolescence and young adulthood. Providers should initiate discussions with the goals to support AYA in making responsible decisions about their sexual behaviors, give accurate information, normalize their feelings about sexuality and attractions, and reduce risks. Young adulthood intensifies sexual risk and although more mature than adolescents, young adults still benefit from approaches targeted to their age and developmental stage.

Pregnancy Prevention and Counseling

For sexually active AYA, providers should support and facilitate the use of reliable contraceptive methods, particularly those that are long acting and reversible (e.g., intrauterine devices, implants) and offer condoms regularly for STI risk reduction. The American College of Obstetrics and Gynecology (ACOG) now recommends LARC as first-line methods for AYA, as they provide more than 99% efficacy and continuation rates of 80 to 90% when compared with other methods.[89]

Barriers to LARC initiation, which include misconceptions on safety and appropriate LARC candidate selection, should be addressed by evidence-based information for both patients and providers. After counseling an AYA seeking contraception, the chosen method should be initiated at that same visit, or a same day referral to a family planning clinic should be scheduled. Delays in provision of contraception, which are not uncommon with LARC (untrained providers, waiting for STI results), can result in unintended pregnancy.

A negative pregnancy test visit is an opportunity to initiate contraception and providers should follow up with AYA on contraceptives frequently. Emergency contraceptive pills should be prescribed or dispensed to all AYA who are not currently using a long-acting contraceptive method. The copper IUD provides an alternate form of emergency contraception that also serves as a long-acting reversible method, ideal for an AYA who has had unprotected sex and desires a long-acting method.

School-based clinics and family planning clinics have been successful in providing confidential contraceptive counseling and services, although a number of school-based clinics are not allowed to provide contraception to adolescents. In addition, state regulations vary as to whether an adolescent can access contraceptive services without parental consent: only 21 states and the District of Columbia allow all minors to consent for these services. Another 25 states allow minors to consent under various circumstances (e.g., prior pregnancy, married).[90] Providers need to familiarize themselves with state regulations and discuss potential barriers and solutions with their adolescent patients.

For pregnant youth, an open, frank discussion about options is essential. Provide a neutral context for the adolescent to express her feelings, consider alternatives, and envision her future using a shared decision-making model.[91,92] (See https://cahps.ahrq.gov/quality-improvement/improvement-guide/browse-interventions/Communication/Shared-Decision-Making/index.html.) Provide support for her interactions with parents and others she involves in her decision. The goal is to provide guidance and tools for the youth to make the best decision for herself.[93] The options of continuing or terminating the pregnancy should be introduced in a nonjudgmental manner and a facilitated referral to follow up prenatal or pregnancy termination care should be provided.

Sexually Transmitted Infections

Discuss the risks of various STIs along with prevention and common presenting symptoms and signs. Preventive strategies include the consistent use of condoms, abstinence, being monogamous, or limiting the number of sexual partners. In addition, AYA should be offered the HPV vaccine (e.g., Gardasil®or Cervarix®), which can be given to both girls and boys aged 11–26 years.[94] The ideal time for the HPV vaccine is before the onset of sexual activity. The use of handouts with age- and language-appropriate information is essential. Treatment should be medically appropriate and include information on how the infection is transmitted, symptoms of the possible complications of the infection, and how to notify recent partners.

The CDC recommends annual chlamydia screening for all sexually active girls aged 25 years and younger.[55] All AYA should be tested for HIV at least once and rescreened as needed. AYA engaged in high-risk behaviors should be rescreened more frequently; guidelines for rescreening vary according to regional prevalence and access to resources.[95] Yearly screening for gonorrhea is recommended for at-risk sexually active AYA (e.g., those with a new partner or multiple partners, those who live in areas with a high incidence of gonorrhea). Pregnant AYA should be tested for chlamydia, gonorrhea, syphilis, HIV,

and hepatitis B. AYA males who have sex with men should be tested at least annually for chlamydia, gonorrhea, syphilis, and HIV, with more frequent testing recommended for those who have sex with multiple partners, anonymous partners, or have sex under the influence of illicit drugs.[55]

HIV testing in LMICs is increasingly available, with an emphasis on provider-initiated testing. Most countries offer HIV testing to all pregnant females in an effort to decrease pediatric HIV infections from vertical transmission. However, there are no guidelines for routine HIV testing among AYA males or nonpregnant females, and the rate of HIV testing by AYA is significantly lower than among adults.[95] The WHO recommends increasing HIV testing and counseling services for AYA through the development of services that are age-appropriately sensitive to this population.[95]

VIOLENCE

The American Academy of Pediatrics Task Force on Violence recommends violence-related assessment including the following: family and individual history of mental illness; domestic, school, or neighborhood violence; gang involvement; substance abuse; family stressors; parental disciplinary attitudes and practices; access to firearms in the home and community; history of fighting; anger threshold; dating violence; and peer involvement in violence-related activities.[96,97] Anticipatory guidance for parents should include discussion of risks of weapons in the home and their removal or safe storage, use of nonviolent disciplinary action, importance of parental involvement and support, and counseling about youth access to media violence. Interventions with youth should focus on teaching strategies for weapon avoidance, nonviolent conflict resolution, and anger management, and encouraging involvement in productive and safe extracurricular activities (see the National Youth Violence Preventions Resource Center: http://www.safeyouth.org). Universal education about healthy relationships and screening for sexual and reproductive coercion and relationship violence are essential approaches to adolescent relationship abuse prevention and intervention. Linkages with domestic violence and sexual assault advocacy organizations facilitate timely and appropriate responses such as safety planning and harm reduction for youth in unhealthy or abusive relationships.[98]

Adolescents who have been victims of or exposed to violence including war or civil conflict may need prompt referral for additional support services; providers must be familiar with local referrals for counseling, antigang/violence and prevention programs. Perpetrators may also suffer depression or posttraumatic stress disorder and need referral for counseling and violence prevention resources.

Substance Use and Abuse

To assess risks for substance use disorders, providers should routinely ask questions with a validated adolescent screening tool (e.g., CRAFFT: http://www.ceasar-boston.org/clinicians/crafft.php). Substance abuse by the immediate peer group and close friends strongly increases the likelihood of initiation in youth. Ask all adolescent patients about their personal as well as their peers' substance use, including tobacco, alcohol, and marijuana. It is critical to assess family substance use and abuse history, as well as parental attitudes toward use, and availability of licit and illicit substances in the home environment.

Discuss the addictive potential of nicotine and offer smoking cessation interventions to adolescents who currently smoke. Given their developmental stage, many adolescents do not respond to warnings about the long-term adverse health outcomes of tobacco use (e.g., lung disease, cancer), but may relate to other adverse effects, such as halitosis, wrinkling, and possible effects on erectile function. In addition to discussing health-related alcohol risks, providers should routinely discuss accident prevention related to alcohol and other drugs, including zero tolerance for driving while intoxicated, designated drivers, and a "no-consequences" alternative for parents when the adolescents may need a ride home.

AYA with identified substance use disorders need prompt referral for treatment to programs and resources that specifically work with AYA. Research-based interventions include pharmacotherapy, cognitive-behavioral therapy, family interventions, and motivational enhancement therapy, and are most successful when they are multidisciplinary and integrated in approach.[99]

Mental Health

Evaluation of mental health must include a comprehensive and thorough history, screening for depression and suicidal ideation, with further inquiries into any family history of depression or suicide. When diagnosing clinical depression, early referral of the adolescent and family for evaluation and therapy is critical. Providers should have a low threshold for referring AYA with psychotic symptoms including delusions and hallucinations. A first episode of hallucinations or delusions may be triggered by substance use. Substance use has been associated with earlier presentation of some psychotic disorders.[77] Early identification and treatment of AYA with potential psychotic symptoms have been shown to improve outcomes.[77]

Evaluate the risk of imminent suicide by determining the extent of suicidal ideation, if the adolescent has formulated a plan, and if there has been a recent attempt. Suicidal ideation and any attempts must be taken seriously and responded to with support and clarity. Hospitalize the patient if there are any concerns about an imminent attempt. This is a life-threatening situation in

which parents must be notified regardless of the breach of confidentiality with the adolescent. Be familiar with community resources such as suicide "hotlines" and suicide prevention programs (see "Resources" section). If the youth is followed up as an outpatient, there must be strong follow-up with close monitoring of any increases in suicidal ideation, plans, or attempts (see Adolescent Health Working Group—the Adolescent Providers Behavioral Health Toolkit: http://www.ahwg.net/resources-for-providers.html).

Homeless Youth

Few interventions with homeless youth have been systematically evaluated, and reviews of the literature have thus far not revealed clearly effective interventions.[100,101] In general, accessible, comprehensive medical services for homeless youth are oriented to the context in which homeless youth live. There is some support for comprehensive, intensive case management as well as bundling services with basic needs.[102] Younger homeless youth accessing runaway shelters are more likely to return home and may benefit from family-focused interventions.[101] Youth who have faced significant abuse, on the other hand, may be unable or unwilling to return home and would be better served by intensive case management and housing assistance.[101]

Youth homelessness may be prevented by primary care providers through early identification of families with a history of significant conflict, sexual or physical abuse, or families unsupportive of their adolescent's sexual orientation or gender identity. These families should be offered support, counseling, and resources including social and behavioral health services. Extension of support and services into young adulthood has been shown to prevent homelessness and improve academic, economic, and social outcomes for foster youth. Providers should be aware of community resources that target this population. Globally, engagement of governmental and nongovernmental organizations and social services and placement of HIV orphans with extended family members can mitigate future risks for this vulnerable population.[103]

Interventions to Improve Success in Chronic Conditions

A study of video-recorded clinic visits found that decision making related to self-management of a chronic condition was an iterative process occurring in three distinct patterns, slow evolution, step-wise, and abrupt decision making. Understanding these decision-making patterns is an essential step toward developing interventions that are appropriate to any given setting and that capitalize on the skills families develop as they gain experience with a chronic condition. Treatment adherence for adolescents with asthma, as with other chronic illnesses, is often poor, and asthma control in adolescent patients is often poorer than younger children with this condition. Interventions to improve asthma adherence can be considered as an exemplar for approaches that engender the needed shift in locus of control from parent to youth in chronic disease management. One report on an innovative program demonstrated improved outcomes of underserved adolescents with asthma.[104] Using the Chronic Care model and guidelines, this program established a special primary care clinic for teens identified with asthma, convened a Teen Asthma Advisory Board, implemented a redesign of the care delivery system, developed systems to improve communication between youth and providers, and developed community linkages and decision support guidelines. With the implementation of this program, the proportion of adolescents with well-controlled asthma increased by 30%, a gain that was maintained over time. The authors concluded that implementing interventions which focused on evidence-based care, self-management support, active outreach, and linkage to community resources can improve care and asthma control in adolescents. These kinds of programs, with intensive home, community-based family outreach, and multidisciplinary teams can be used as models for management of other chronic conditions in underserved adolescent patents.[105]

Using Technology and Social Media

Technology and social media may represent future tools to improve management of chronic conditions, as well as other youth-related issues. Studies indicate that 95% of American teens are online at least sometimes, and this connectivity increasingly moves with them on the rapidly developing variety of mobile devices.[106] The use of technology with teens is a growing area of research and has great potential for the management of chronic conditions in teens.[107,108] Recent reports indicate that (1) teens prefer to receive text messages rather than e-mail, (2) computer-based screenings are acceptable to teens, (3) Web sites that address specific domains of teen health should be easy to use, and (4) social media can play a role in teen health and chronic disease management. Furthermore, the resources or sites need to be connected to the teen's personal experience with a group or organization that focuses on the teen's specific condition and confidentiality must be assured.[106]

CONCLUSION

Reducing vulnerability in adolescence and young adulthood requires a multidisciplinary approach that views AYA in the context of their personal characteristics,

family, peer group, school environment, and community. Successful care is based on respect for the emerging autonomy of the adolescent and young adult, while providing for adequate assessment of family and social support, and intervening when necessary. National guidelines exist that extensively outline recommendations for routine preventive services. (See the American Academy of Pediatrics' Bright Futures Guidelines: https://brightfutures.aap.org/pdfs/Guidelines_PDF/18-Adolescence.pdf). The art of working with AYA lies in identifying those who are at increased risk for preventable morbidity and mortality and working with interdisciplinary collaborative teams to intervene with appropriate resources. Providers should become familiar with community-based organizations that promote prevention and positive youth development and can help AYA negotiate risky environments and behaviors. Clinics that serve AYA exclusively, providing youth-friendly and appropriate services, can be a valuable resource to community providers. Early and effective intervention with AYA can impact health and social outcomes throughout adolescence and adulthood.

Care of Adolescents and Young Adults (AYA)

- Develop youth-friendly systems of care.
- Treat patients with respect.
- Do not trivialize concerns.
- Identify positive adult role model in patient's life.
- Work collaboratively both in health delivery systems (clinicians, social workers), schools (teachers, administrators, school nurse), and community-based organizations (case managers, mentors).
- Do not be a parent or a peer.
- Assure confidentiality of services.
- Assess school performance.
- Support parents and identify stresses of parenting adolescents.
- Express concern and compassion for healthy outcomes for AYA.
- Become familiar with local resources for behaviors that put youth at risk: substance abuse, violence prevention and gang task force programs, mental health services, sexual and reproductive health services, homelessness, immigration.
- Be nonjudgmental.
- Normalize sexual feelings and attractions.
- Respect and acknowledge maturation while continuing to provide appropriate supports.
- Use every clinical encounter to update psychosocial assessment to identify risks.

The Psychosocial History Addressing Key Domains Affecting Youth

H	**Home**	
		Who lives with you? Where do you live?
		Can you talk to anyone at home about stress? (Who?)
		What are relationships like at home?
		Have you or your family ever been homeless or lived in a shelter?
E	**Education/Employment**	
		Are you currently in school?
		Tell me about your school? Is it a safe place?
		Have you been bullied?
		Do you feel connected to your school? Do you feel like you belong?
		What language do you speak at home? (i.e., What is your first language?)
		Do you have problems understanding your teachers or reading?
		How are your relationships with teachers and classmates (or coworkers if employed)?
		Have you ever failed a grade or dropped out of school?
		Are there adults at school you feel you could talk to about something important? Which?
		Are you working? Where? How much?
E	**Eating**	
		Does your weight or body shape cause you any stress?
		Have you had any recent changes in your weight? Do you (or your family) have enough food for regular meals?
		Have you dieted in the last year: How? How often?
A	**Activities**	
		What do you do with your friends or family for fun?
		What activities (sports, clubs, groups, religious, or spiritual) do you participate in?
		How many hours do you usually spend daily in front of a screen, such as computer, TV, or phone?
		What are your favorite hobbies, books, music, and so on?
D	**Drugs**	
		Have you or your friends ever tried cigarettes or electronic cigarettes, alcohol, or other drugs? What have you tried?
		Do you observe (see/or observe) drug use near your home or school?
		How often have you used them, and how much at one time?
		Do you ever drive or ride in a car when you have been using alcohol or drugs?

Does anyone at home use tobacco, alcohol, or other drugs? (Use CRAFFT screen)

S **Sexuality**

Have you ever been in a romantic relationship with anyone? With boys, girls, or both?
How many partners have you had?
Have you ever been pregnant or had a sexually transmitted infection?
(For males)—Have you ever had any children or impregnated a partner?
Have you used anything to prevent pregnancy or sexually transmitted infections?
Have you ever been forced to have sex against your will?

S **Suicide and Depression**

What do you do when you are feeling sad, angry, or hurt? (PHQ-A screen)
Have you ever felt so sad, angry, or hurt that you have wanted to hurt or kill yourself?
Have you had any trouble with sleeping, or sleeping too much?
Have you had any changes in appetite or concerns about eating?

S **Safety**

Do you feel safe at home and school? In your neighborhood?
Are there guns or other weapons in your home?
Do you or any of your friends have a gun?
Have you ever been arrested or sent to a juvenile detention center?
Have you or any of your friends ever been injured as a result of an attack with a weapon (gun or knife)?
How often do you wear a seatbelt when in a car?
When was the last time you sent a text message while driving?
Tell me about a time when you have ridden with a driver who was drunk or high? When? How often?
Have you ever met in person (or plan to meet with) anyone whom you first encountered online?

Adapted from Klein DA, Goldenring JM, Adelman WP. HEEADSSS 3.0: The Psychosocial interview for adolescents updated for a new century fueled by media. Contemporary Pediatrics 2014:16-28.

Note: Consider an alternate screening tool which begins with a focus on strengths: SSHADESS: Strengths, School, Home, Activities, Drugs/substance use, Emotions/depression, Sexuality, Safety.

DISCUSSION QUESTIONS

1. Compare the difference in approach you would use in risk reduction counseling between a 13-year-old and 17-year-old patient.
2. In addition to the risk of pregnancy, identify areas of concern for Rosa (consider developmental, legal, and cultural). How would you prioritize interventions for her?
3. Describe the characteristics of youth-friendly services.
4. Describe the ideal multidisciplinary team that would best meet the needs for Jared, the homeless youth.

RESOURCES

Global youth data and perspectives:

The 2014 WHO report, Health for the World's Adolescents: A Second Chance in the Second Decade, presents a global overview of adolescents' health and health-related behaviors, including the latest data and trends, and discusses the determinants that influence their health and behaviors—http://apps.who.int/adolescent/second-decade/.

General provider resources:

Adolescence guidance from Bright Futures: https://brightfutures.aap.org/pdfs/Guidelines_PDF/18-Adolescence.pdf.

Adolescent Health Working Group Provider Toolkits (Adolescent Health Basics, Understanding Minor Consent and Confidentiality, Behavioral Health, Body Basics, Sexual Health, Trauma and Resilience): http://www.ahwg.net/resources-for-providers.html.

Community-driven partnerships with resources to develop protective factors and best practices for teens: http://www.allaboutkids.umn.edu/konopka/.

Family Acceptance Project (materials to use with families with LGBTQ children): http://familyproject.sfsu.edu/publications.

Society for Adolescent Health and Medicine: http://www.adolescenthealth.org.

Psychosocial screening tools:

Psychosocial History Resource Center (HEEADSSS 3.0, SHADES, video instructions, articles, etc.): http://contemporarypediatrics.modernmedicine.com/resource-center/heeadsss3-0.

Ginsburg KR. Viewing our adolescent patients through a positive lens. Contemp Pediatr 2007:24(1):65-76.

Klein D, Goldenring J, Adelman W. HEEADSSS 3.0: The psychosocial interview for adolescents updated for a new century fueled by media. Contemp Pediatr 2014:16-28.

Depression Screening Tool PHQ-A: http://www.uacap.org/uploads/3/2/5/0/3250432/phq-a.pdf. Scoring instructions: http://www.cappcny.org/home/documents/phq 9 teens scoring.pdf.

PHQ-A: Johnson JG, Harris ES, Spitzer RL, Williams JBW. The Patient Health Questionnaire for Adolescents: Validation of an instrument for the assessment of mental disorders among adolescent primary care patients. J Adol Health 2002;30:196-204.

Substance use screen: CRAFFT: http://www.ceasar-boston.org/clinicians/crafft.php.

Adolescent legal resources:

National Center for Youth Law: http://www.teenhealthlaw.org/

Guttmacher Institute. State policies in brief: an overview of minors' consent laws. 2014. Available at: https://www.guttmacher.org/statecenter/spibs/spib_OMCL.pdf. Accessed January 7, 2014.

Foster youth resources:

FosterClub is a national organization whose mission is to lead the efforts of young people in and from foster care to become connected, educated, inspired and represented so they can realize their personal potential and contribute to a better life for their peers. These youth activists have created a Transitions Toolkit: https://www.fosterclub.com/_transition/article/transition-toolkit

Homeless youth resources:

Transitional Living Program for Homeless Youth: http://www.benefits.gov/benefits/benefit-details/619.

National Association for the Education of Homeless Children and Youth: http://www.naehcy.org/educational-resources/youth.

Youth Drop in Centers: http://homeless.samhsa.gov/channel/youth-drop-in-centers-508.aspx.

Educational resources:

Thread engages underperforming high school students confronting significant barriers outside of the classroom by providing each one with a family of committed volunteers and increased access to community resources in Baltimore, MD: www.Thread.org.

Healthy Relationships and Relationship Abuse Resources:

Break the Cycle: Empowering Youth to End Domestic Violence: http://www.breakthecycle.org.

Stop Bullying Now: http://www.stopbullyingnow.com/index.htm.

Love is Respect: http://www/.loveisrespect.org/.

Pregnancy prevention resources:

CDC Teen Pregnancy Prevention, containing resources for parents, providers and teens: http://www.cdc.gov/teenpregnancy/aboutteenpreg.htm—Disparities.

National Campaign to Prevent Teen and Unplanned Pregnancy, Counting It Up: The Public Costs of Teen Childbearing: http://thenationalcampaign.org/why-it-matters/public-cost. Accessed February 5, 2015.

Sexual and reproductive health resources:

Advocates for Youth (sex education curriculum and policy advocacy tools): http://www.advocatesforyouth.org/for-professionals/sex-education-resource-center.

The National Campaign to Prevent Teen and Unplanned Pregnancy provides data and relevant publications at http://thenationalcampaign.org/.

ACOG Committee Opinion #539, "Adolescents and Long-Acting Reversible Contraception: Implants and Intrauterine Devices" provides clinical information and a slide set for providers. http://www.acog.org/About-ACOG/ACOG-Departments/Long-Acting-Reversible-Contraception/LARC-Clinical-Resources.

CDC Teen Pregnancy Prevention: resources for parents, providers and teens. http://www.cdc.gov/teenpregnancy/aboutteenpreg.htm#Disparities.

"Let's put birth control back on the agenda." TED talk by Melinda Gates. https://www.ted.com/talks/melinda_gates_let_s_put_birth_control_back_on_the_agenda.

Vernacchio Al. For Goodness Sex: Changing the Way We Talk to Teens About Sexuality, Values, and Health. 1st ed., New York: Harper Collins Publishers; 2014. A novel look at sex education by a high school sexuality teacher.

CDC's Teen Friendly Health Visit outlines the components of a teen-friendly clinic visit for sexual and reproductive health services. http://www.cdc.gov/teenpregnancy/healthcare-providers/teen-friendly-health-visit.htm#elements.

Bedsider for Providers links to free information, resources, patients materials and interactive tools for providers of sexual and reproductive healthcare for AYA. http://providers.bedsider.org/.

Adolescent pregnancy and parenting resources:

The National Crittenton Foundation provides counseling, education and support for young mothers through a family of agencies located across the US. http://www.nationalcrittenton.org/who-we-are/.

The National Fatherhood Initiative provides resources for fathers, including new young fathers. http://www.fatherhood.org/.

The Healthy Teen Network has links to resources for working with pregnant and parenting teens. http://www.healthyteennetwork.org/working-pregnant-parenting-teens.

"Working with Pregnant and Parenting Teens Tip Sheet" provides information and resources for providers. http://www.acf.hhs.gov/sites/default/files/assets/preg.

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Chapter 22

The Family as the Context for Care

George William Saba, PhD and Teresa J. Villela, MD

Objectives

- Describe the challenges of providing care to underserved populations in the context of family.
- Define alternative family structures.
- Define a model of care centered on the family.
- Outline key domains of family functioning.
- Describe the process and content of family assessment.
- Illustrate family-focused interventions.

INTRODUCTION

Mrs. Escalante, a 40-year-old single parent with uncontrolled hypertension, lives with her son, Jimmy, who is 14 and has diabetes. Doctors rely on Jimmy to interpret for his mother. Medicaid covers his care, and although his mother works, she is undocumented, uninsured, and ineligible for Medicaid.

Families play an extraordinary role in the ways people experience the world and are the principal channel for the transmission of culture. Negotiating society's demands and experiencing illness, health, and caretaking are all learned within the context of families. Hence, patient-centered care must also be crafted using the family as a framework.

Health care in the United States and other systems with a narrow biomedical perspective, however, focus on the individual patient and not the family. Increasing evidence suggests that by broadening the focus to involve a patient's family, providers may be better able to understand the onset and development of disease and improve treatment outcomes.[1-6] This chapter addresses how considering the family as the context of care can improve the overall health of families in underserved populations.

DEFINING THE FAMILY

During the last century, the nuclear family—consisting of two heterosexual, legally married adults living with their biological children—was promoted as the ideal family structure. This exclusionary definition has been challenged: it sanctions only heterosexual unions and legally married partnerships, and it diminishes blended families, families with adoptive children, extended families, and kin relationships.

In fact, the traditional nuclear family has never accurately represented the "typical" family structure in the United States. Only 20% of respondents to the 2010 census might be considered part of traditional families—consisting of a married couple with children. Single-parent households comprise 9% of the total households in the United States and 24% of children live only with their mothers, and 4% live only with their fathers.[7] Lesbian and

gay Americans living in committed relationships in the same residence are estimated to total 3.1 million. Sixteen percent of same-sex households include a biological, step, or adopted child.[8]

Families internationally are in flux, though two-parent families in some parts of the world are more common than they are in the United States. In the Middle East and in Asia, a majority of children live with two parents. In Europe, North America, Oceania, South America, sub-Saharan Africa, about 20% of children live either with someone other than their biologic parent or in a single-parent household. Many European countries estimate that the number of children living with one parent will increase over the next 15 years. Extended families' structures that include parents and relatives are common in Asia, the Middle East, South America, and sub-Saharan Africa.[9]

Consequently, alternative definitions of families should be recognized: a family represents a significant group of intimates with a history and a future or any group of people related biologically, emotionally, or legally.[10]

CHALLENGES TO PROVIDING CARE TO FAMILIES FROM UNDERSERVED POPULATIONS

FAMILY CAPITAL AND SOCIAL CAPITAL

All families have capital that helps them successfully navigate the world.[11] This capital results from economic wealth, maintaining health, and obtaining a sound education. These areas are interrelated; success in one area often determines success in the others.

A family in disarray may place its members at risk for increased financial problems, poor health, and an inability to function in society. Underserved families often store little capital (economic or educational) because of the interaction of poverty, limited access to health care, and inequality in education. However, they may be rich in social capital; relationships bind individuals together, forming networks of cooperation and reciprocity. Strong family cohesion can provide sufficient critical support and might eventually lead to relative prosperity.

Struggling families may develop significant relationships with those working with social institutions (e.g., social welfare offices, refugee and immigration services, county health departments, and the criminal justice system). The benefits of these institutions may be counterbalanced by a loss of control, privacy, and autonomy. Institutions may also have considerable involvement in the intimate functioning of a family and, by assuming familial roles, undermine a family's sense of competence and self-care. Social services involvement may be intrusive and alienating. For example, a child with iron deficiency might be treated differently if she is from a middle-class family compared with a poor one. In the first instance, she might receive iron therapy and nutritional counseling. In the other, she and her family, appropriately or not, might face scrutiny from a social perspective (as in screening for neglect).

IMPACT OF POVERTY

In 2012, a total of 9.52 million families (11.8%) lived below the federal poverty level (FPV), up from 7.2 million (9.6%) a decade before. Poverty rates for racial and ethnic groups were as follows: whites (9.7%), Latinos (25.6%), African American (27.2%), and Asians (11.7%).[12] While the official FPV for a family of four is $23,850 a year, it is estimated that this same family would need twice that amount to afford basic expenses (food, housing, child care, health insurance, transportation, and utilities).[13] Importantly, other basic expenses, for example, clothing, cleaning, school supplies, etc., are absent from this list.

For anyone living in poverty, going to the doctor's office incurs huge costs (e.g., transportation, taking time from work, paying for the visit, paying for prescribed medications). The additional cost of family members accompanying them may prove prohibitive. Families may make choices between paying for health care and meeting other basic needs and may postpone preventive and chronic care, feeling they can only afford these services when seriously ill.

ACCESS TO CARE

The financial, physical, and emotional well-being of all members of a family is jeopardized when any individual within the family lacks adequate health insurance coverage. Illness and medical bills in a family contribute significantly to a family's debt. In the United States, medical debt is the most common reason for families to declare bankruptcy and undermines families' housing stability and educational opportunities.[14] Lack of insurance also makes it difficult for families to receive nonfragmented health care. Compared with insured families, uninsured parents are seven times more likely to delay or forego medical care for their children and not fill their prescriptions.[15] Uninsured parents also postpone their own care to pay for their children's.[16]

EDUCATION

Underserved families often experience poor health outcomes related to their impoverished education, low health literacy, and the inability to communicate effectively with their clinicians. The poorly educated, illiterate family may feel less empowered to take control of their care. They may fail to ask questions or admit a lack of understanding

about their care for fear that their clinicians will judge them.[17] Non–English-speaking patients often receive care from clinicians who do not speak their language and have minimal access to trained interpreters. Turning to English-speaking family members, often children, to interpret, they may not realize that sensitive information may be filtered, incomplete, or distorted. Clinicians might erroneously judge the family as noncompliant, unmotivated, or manipulative.[18] A supportive, involved family can mitigate some of the risks of low education and poverty. Adult children, spouses, or other family members who help in the daily tasks of self-care may mitigate many health risks and may be one explanation why some immigrants have better than expected health outcomes despite low socioeconomic class.

CONCEPTUAL FRAMEWORKS FOR PROVIDING CARE TO FAMILIES

BIOMEDICAL MODEL

In the biomedical model, the family plays a minor role in care.[19] This model of care greatly restricts how clinicians think about health and illness, the causes of disease, the focus of treatment, and the roles of clinicians, patients, families, and delivery systems. With some exceptions, most clinicians only consider patients' families when looking for genetic predispositions for disease or for assistance in difficult treatment decisions. Some may even prefer not to interact with family members, because it requires extra time.

The biomedical model also centers the design of health-care systems on the individual patient. Examination rooms generally are large enough for only two people: the patient and the clinician. Medical charts are individually constructed and do not link the care of family members even within the same office setting. Clinicians may not realize that their patients' family members also receive care in the same health center.

CLINICIAN'S PERSONAL MODEL OF MEDICINE

In addition to the biomedical model's dominance in the culture of medicine, clinicians bring their own assumptions and values to their practice.[20] These beliefs, a complex product of one's personal family experiences, society's values, and one's professional training, influence all clinical decisions. Consciously or unconsciously, clinicians hold assumptions about what constitutes a family; the degree to which family structure and family members are responsible for the development and maintenance of illness; and what the clinician's own role and the family's role should be in the patient's care. Common pitfalls in working with underserved families are shown in Box 22-1.

Box 22-1. Common Pitfalls in Working with Underserved Families

- Assuming a stereotypic view of what constitutes a family.
- Ignoring the important perspectives on illness, health, and functioning that can be garnered from understanding a patient's family.
- Allowing one's personal views of family to form unconscious assumptions about patients' family dynamics.
- Becoming entangled in a family's unproductive patterns of interaction, rather than introducing new, healthier ones.
- Seeing only the challenges that families face and forgetting about their internal strengths and resources.

CROSS-CULTURAL DIFFERENCES

The culture of health care may differ considerably within families, across generations, and among family members who immigrate at different times or acculturate at different rates. Clinicians are poorly equipped to deal with such differences. Although cultural competency has once again reached national attention, many of the offered educational interventions still rely on stereotyping the commonalities of racial and ethnic groups (e.g., "African-American families expect …, Latino families believe …, Asian families think …"). A more nuanced, systems-based approach acknowledges the importance of shared history within a racial, ethnic, or immigrant group while focusing on the unique experiences of an individual family, its members, and their complex relationships (see Chapter 14). Interventions that educate clinicians about skills they need for this approach are rare.[21,22]

IMPROVING CARE FOR UNDERSERVED FAMILIES

Many of the challenges to optimal health for underserved families are linked to social, political, and economic forces. Understanding the resources, strengths, and limitations of a specific family can help mitigate these forces and improve the health of family members. To deliver family-oriented care, providers need to accurately define the patient's family and understand how a family functions as well as advocate for social and political change (see Chapter 8).

FAMILY SYSTEMS APPROACH

A family systems–oriented or biopsychosocial approach to care expands the biomedical model to include broader forces that influence health and significant interpersonal relationships.[23,24] This paradigm assumes that without

focusing on the complex interactions among individuals, their families, and society, one cannot truly understand the individual. Providers must place people in the context of family, time, culture, and society to begin to appreciate who they are.

Clinicians should find out about their patients' intimate relationships, whether connected legally, biologically, or through shared emotional experience. Families of choice that are not legally sanctioned (e.g., same-sex partnerships, kinship foster care) face special challenges such as not sharing insurance benefits, lacking access to information, and being denied involvement in legal and health-care decision making.

On the other hand, some patients may deny having any family or minimize the degree of interaction with family because of previous family strife and estrangement. However, past family interactions may still have profound effects on one's overall health. For example, sexual abuse in poor families has more devastating and longer intergenerational effects than in more affluent families, primarily because of fewer resources.[25] Even when the abuser is deceased or estranged, the relationship patterns in the family can have profound power, and a clinician can miss important information about how these patterns operate.

The biomedical model guides clinicians to examine the relationships between organ systems and physiology. The systems approach, in contrast, broadens the view to explore the relationships between these "internal" systems and an individual's "external" interpersonal and social systems. Examining these relationships allows clinicians to learn more and be more effective in their care than investigating pathophysiologic processes alone. For example, rather than considering only the level of insulin resistance complicating a patient's diabetes, clinicians can explore interconnections between insulin resistance and family and work life. Central to this analysis is discovering how a patient's view of health and illness affects the care of his or her diabetes and what role the disease plays in family interactions.

Relationships are the essence of this approach. A patient's health and illness are conceptualized in the context of both their physiologic and interpersonal functioning. The focus is on discovering how the health and illness of any one member affects the multiple relationships within each family. Even when seeing a patient alone, a clinician can inquire about family as an essential, not an optional, aspect of ongoing care.

Learning how a patient's illness affects the family and how the family affects the illness needs to be determined early and continually in clinical care. To enrich the clinician's understanding, gathering other family members' perspectives is invaluable. Asking family members their views on the patient's condition, how the illness has affected family life, and what they try to do to help reveals the similarities and discrepancies between the patient and family's perspectives. With this knowledge, clinicians can support family patterns that aid in the patients' care and challenge those that seem to hinder it. Too frequently, clinicians spend months or years focusing on the biomedical management of a chronic illness only to call in a family member out of frustration. Although this can be valuable, calling family members only as a last resort risks losing early opportunities to build on familial strengths and may even unwittingly provoke stressful family reactions.

CREATING A NETWORK OF CARE

The family systems paradigm attempts to move beyond the patient–clinician relationship to develop a network of care. This network creates a context for a relationship between the "patient–family" subsystem and the "clinician" subsystem. The "patient–family" subsystem can include family members, friends, community support (e.g., church, cultural groups, social clubs), institutions (e.g., social welfare, immigration and refugee health, work). The "clinician" subsystem can include the primary care clinician, nursing staff, subspecialists, interpreters, social workers, and mental health staff. This network of care operates in a particular health-care context (hospital, clinic) that contributes its own influences (e.g., treatment guidelines and available resources).

Clinicians should recognize that they too have a "family context" and personal model of medical care. Reflecting on their own assumptions about underserved families, values about family structure, and beliefs about patients' families, and their own role in health care is important. A common pitfall for clinicians working with underserved families is to assume the role of rescuer. This not only can lead to clinician burnout but can also seriously undermine the competencies of a family. Articulating one's model of medicine can shed light on points of convergence and divergence between the clinician, patient, and family's expectations.

THE FAMILY AS THE CONTEXT OF CARE

FAMILY FUNCTIONING

Within a family, individuals group into various subsystems according to their identity or function (e.g., partners, parents, generations, siblings, gender). A family's rules guide interaction and function, telling who to do what, how, and when it should be done. These rules dictate patterns of behavior that become ingrained in a family's life and in turn reinforce the fabric that holds family rules in place. Family rules govern key domains of family and individual functioning that are important to how a person

conceives of illness, health, and medical treatment. These key domains of family functioning include (a) boundaries, (b) decision making, (c) conflict, (d) roles, (e) protection, and (f) caretaking.

Boundaries

Boundaries exist between families and the external world and among members of a family. Boundaries protect the family and its members from unnecessary intrusion and allow sufficient interaction to promote its development. All major life transitions (e.g., pregnancy, adolescence, migration, disease diagnosis) require renegotiation of these boundaries.

Rigid boundaries make it difficult for the family to assimilate new information, interact in new ways, and grow. This rigidity can lead to a disengagement of its members. Disengaged families require significant events to trigger resonance between members: a child may have to be arrested before parents recognize a problem exists; a chronically ill parent may need to be hospitalized before her family acknowledges that she is seriously ill. Some families who fear intrusion from social and public institutions develop rigid boundaries to protect themselves and, consequently, become isolated and unable to access available health-care services.

On the other hand, permeable boundaries jeopardize the ability of individual family members to operate autonomously. "Enmeshment" is the term used to describe extreme proximity and intensity in family relationships in which boundaries are not well demarcated. Permeable boundaries allow a rapid resonance of behavior from one person to another, undermining each member's autonomy. Individuals may have a difficult time distinguishing personal needs and priorities from those of other family members. For example, in an enmeshed, obese family, a child might feel it would be disloyal to attempt to lose weight.

Decision Making

Each family has rules that guide which family members are responsible for which decisions, clarifying who has power and authority. One family member may be responsible for decisions external to the family (e.g., housing, earning money), whereas a different one manages decisions within the family (e.g., how the money is spent). How families make decisions about health care (e.g., when to seek care, what treatments should be pursued) may mirror their general decision-making patterns. Challenges to decision-making patterns can cause significant family stress. Consider a woman who emigrated from Vietnam 15 years ago with her young children. When her husband escaped from a reeducation camp and joined them years later, he expected to resume his role as decision maker and she was reluctant to relinquish it, leading to an unexpected familial stress. A system-based intervention would encourage the couple to renegotiate new roles and emphasize the strengths of their bond, which survived the hardships of war and relocation.

Conflict

Families deal with conflict in various ways. Rules guide how they face conflict and whether they choose to resolve or avoid conflict. Unresolved conflict can result when families avoid acknowledging disagreements because they believe that they threaten their relationships. Unaddressed disagreements increase stress and affect overall health. Families reproduce these patterns of dealing with conflict in their relationships with health-care professionals, profoundly affecting communication, decision making, and follow-through.

Consider a family (parents and young children) who emigrated from Guatemala. As the children reach adolescence, parents and children differ dramatically in expectations about independence. The adolescents, wanting to avoid conflict, choose not to tell the parents about new values and beliefs. The parents, who do not speak English and mistrust the culture their children have adopted, fear losing touch with them but are afraid to confront them and lose them altogether. This mutual avoidance of conflict leads to greater distance, which all experience as stressful. In this family system, a health problem (e.g., unplanned pregnancy in one of the teenagers) might not be addressed promptly because to do so increases conflict.

Role

Family functioning is increased when members are assigned specific roles such as nurturing, caretaking, maintaining financial security, decision making, and parenting. Roles can be guided by sociocultural values or interpreted idiosyncratically within the family. Family members may or may not agree with a role assigned to them. When someone is sick, their ability to carry out their role is compromised, and his or her tasks need to be shared, assumed by another family member, or go undone.

Consider a single parent whose work-related injury causes a long-term disability. Because she is undocumented, she cannot apply for worker's compensation and has never had health insurance. She can no longer carry out many of her roles (e.g., earning money, caring for her children). Her 16-year-old daughter leaves school to get a job, whereas her 12-year-old daughter manages the household.

Protection

Protecting its members is a key responsibility for families. Overprotection can occur in families whose internal boundaries are enmeshed and can develop in families when members face a serious chronic or life-threatening illness. A desire to prevent worsening of the illness can

cause family members to protect the person from any risk, often leading to a problematic relationship. For instance, a child diagnosed with asthma at the age of 4 years may warrant a high degree of protection (e.g., ensuring allergen-free environment, obtaining medication refills on time, ensuring daily dosing) that can be readily provided by his parents. However, if these patterns of protection continue into young adulthood, both parents and child will be poorly prepared for essential developmental growth.

Lack of protection can occur within and between families and the outside world. Within the family, lack of protection can lead to abuse and incest. Through neglect, members may be left vulnerable to violence and intrusion from public institutions.

Caretaking

Families develop patterns of caretaking and clear expectations for how family members are to act when sick and how responsible they are for their own care (e.g., to continue with duties without complaint, to be excused from expected tasks). For example, expectations among racial/ethnic groups receiving care in urban, public health clinics vary widely: some patients identify themselves as responsible for managing their own care, whereas others rely on their families.[22] Families bring these caretaking patterns to relationships with the health-care team, often expecting clinicians to adhere to these unspoken family rules.

FAMILY ASSESSMENT

Family assessment includes formulating a "family database," a detailed description of the family network; analyzing the patterns of familial functioning in the key domains described in the preceding section (i.e., decision making, conflict); analyzing familial strengths and views on health problems; and organizing and charting this information effectively. Assessment is an essential component of a family meeting (Table 22-1).

Family Database

To understand key relationships in a patient's life, clinicians need to develop and maintain a family database. They should inquire who is in the family, who lives in the household, where other key members live, and what is the frequency of contact among them. They should also clarify institutional relationships (social workers, parole officers, school counselors, case manager, home health-care providers), including frequency of interaction and contact information.

Analysis of Family Functioning

To identify patterns in family functioning, clinicians can ask open-ended questions: What is your role? How do you handle disagreements? When families cannot articulate a pattern, a more behavioral, health-specific inquiry may be necessary: When you become symptomatic, what do you do? Do you tell anyone?

TABLE 22-1. Conducting a Family Meeting

- Meet and introduce all members (e.g., family, friends, other agency, or health-care personnel). Express appreciation for their attendance.
- Clarify the purpose for the meeting and some guidelines:
  - Overall treatment goal (e.g., "We wanted to get everyone together to help me best care for Eleanor. You are all very important in this process, and I would like to get your ideas on how we can all help")
  - Goal for the meeting (e.g., "I want to hear from each of you, including Eleanor, how you think her illness has affected you and what you have done to try to help her.")
  - How long the meeting will take and whether you will meet with everyone together for the whole time or in smaller groups
- Include everyone in your gathering of information; be attentive not to exclude children, those who may be reticent, or those who have a language or communication barrier.
- Gather each member's perspective on:
  - Family functioning
  - Family strengths
  - Views of illness/problem
  - Solutions: Include solutions that have been attempted as well as those only considered.
- Summarize and clarify the information gathered to ensure accuracy.
- Reframe the illness in the context of relationships and strengths.
- Create enactments during the meeting to experiment with and experience new interaction patterns of behavior.
- Elicit any questions or concerns.
- Develop an agreed-upon plan and clarify everyone's role, including the clinician, in the plan.
- Construct tasks for family members to engage in outside of the office that evolve from the work accomplished during the meeting; ensure understanding of the tasks and family members' agreement to do them prior to the next appointment.
- Determine the timing of the next appointment and who should attend.

Family Strengths

Families have strengths and resources that they cultivate and use throughout their lives (e.g., unquestionable love and trust, steadfast faith in God, ability to be creative in a crisis, strong network of friends). Families may have invoked these strengths to transcend previous difficult episodes in their lives (e.g., immigration, untimely death of a loved one, experiences of abuse or torture, war) but forget they could apply them to a current health crisis. Clinicians should ask family members to identify their own strengths. They should also reflect to the family the strengths that they observe in clinical interactions.

Views of Illness/Problem

Families develop a view, or a "story" of what may be occurring during a health crisis. Individual family members may all share the same story or vary in their perception.

These variations may be openly acknowledged or operate more covertly to avoid disruption or censure. Clinicians should assess each family member's views about the current health issue by asking each member in turn: What is your understanding of the problem? Do you think others share your perception? What are you, in particular, most worried about?

Charting

Genograms and other methods of visually cataloging family composition and relationships can provide useful means for charting information and making it accessible for future visits. Computerized medical records could facilitate this process by allowing individual patients' charts to be linked to create a central "virtual" family record that includes important family data.

Questions may arise for clinicians about privacy and sharing of information among family members. Legal requirements should serve to guide what information should be revealed to family members or outside agencies (e.g., danger to self or others, child abuse). Beyond professional guidelines, clinicians should not share information among family members unless given permission to do so. However, clinicians can help facilitate open discussion and disclosure of important information.

FAMILY-FOCUSED INTERVENTIONS

Reframing

The family's view of how they can deal with the current health condition may be inadequate to help mobilize them toward full participation in the healing process. It may emphasize fear, weakness, and blame. Clinicians should consider whether changing the view, or reframing it, would allow the family to maintain hope and activate resources. Reframing should highlight the family's strengths to promote a sense of control.

Box 22-2. Central Steps in Family Enactment

1. Identify a pattern of interaction relevant to the current health issue.
2. Describe the pattern to the family, delineating the rule-governed sequences of behavior that lead to unproductive outcomes.
3. Ask the family to reengage in the pattern and suggest trying a new behavior to change the sequence.
4. When the new pattern changes how people interact, have the family repeat it either immediately or as a task at home.

Box 22-3. Tasks

Prescribe tasks that:

- Tie in with the focus of the visit;
- Are practical, measurable, and doable;
- Are clear to each family member (have each person report his or her understanding of the task); and
- Include all family members, even if some members' role is simply to observe.

Box 22-4. Example of a Family Systems Approach

Jimmy's new doctor at the health center, Dr. Rodgers, speaks Spanish to include the mother. When she asks their respective views on his diabetes, Mrs. Escalante answers that he refuses to eat properly and exercise.

Jimmy then answers that his mother is overprotective. He has refused to give himself his insulin injections, relying on Mrs. Escalante to do it (enmeshed, caretaking, overprotection). They both feel hopeless that the other will change (family's view).

In further family assessment, Dr. Rodgers discovers that Mrs. Escalante and Jimmy immigrated from El Salvador 12 years ago, after Jimmy's father was killed. They have relatives in El Salvador with whom they talk monthly, and she sends money to them when she can. They live in a house with another family, but are isolated. Jimmy sees a counselor at school "who at least doesn't treat me like a baby" (family composition and important people).

The doctor notices that mother and son are emotionally close and have a strong affection for each other. They immigrated together and established themselves in the United States (strengths). Doctor Rodgers suggests to Jimmy that his mother's "overprotectiveness" springs from her deep concern, and explains to both that she sees Jimmy's behavior not as "rebellious" but as "experimenting" with the normal autonomy of adolescence. She challenges them to acknowledge that they are at an important transition phase in their life, and that some of the rules that have helped them will need to change. Mrs. Escalante's intrusion and Jimmy's lack of initiative may have worked when the family was at an earlier developmental stage; but things now need to shift.

Dr. Rodgers strongly assures them that they will succeed given all that they have previously accomplished as a family (reframing, strengths). She suggests that Mrs. Escalante teach Jimmy to give himself his injections. They try this out in the visit with success (enactment). They are instructed to continue this "hand over" of responsibility as a step toward a new way of being a family (task).

Enactment

One intervention to help families learn new ways of interacting is called enactment. This is a structured process to help families experience new interactions around familiar issues, leading to new patterns (Box 22-2).

Tasks

Changes in behavior patterns can be reinforced between appointments through tasks (Box 22-3). Clinicians should follow up on the outcome of assigned tasks at subsequent visits. This highlights the important message that the clinician takes the task seriously and increases the chances that a family will engage in future tasks. Any outcome of the task yields valuable information: forgot to do it; tried to do it, but failed; tried to do it, and succeeded. Why families forget or "try and fail" can reveal the complex process of achieving change. The results of a successfully completed task can reveal whether it yielded change and whether there were any unexpected negative or positive consequences (Box 22-4).

CONCLUSION

The family remains one of the most important contexts through which the world is experienced; yet, it does not hold the same place in how health care is conceptualized or delivered. Although this handicaps care for all families, underserved families experience even greater fragmentation and marginalization, given the social, cultural, economic, and political challenges they face; they may not have sufficient "family capital" of good health, solid education, or accumulated wealth to overcome barriers to care.

By introducing conceptual and practical changes into the US health-care system and society, clinicians can improve the care of underserved families. Through social advocacy, they can influence the political process to facilitate equal access to services. By shifting from a biomedical approach to a systems-oriented one, they can center care within the context of each underserved family.

DISCUSSION QUESTIONS

1. Describe your personal beliefs and values about underserved families. How might these beliefs and values affect your clinical care?
2. What benefits and difficulties do you anticipate in adopting an approach to clinical care that sees patients in the context of their families?
3. How would you design a system that provides health care based on a paradigm that views the family as the context for care?

Recognize the family as the context for patient care:
- Seek family members' perspectives.
- Involve family members in care plans.

Identify family members and important relationships.
- Remember alternative definitions of family.
- Identify institutional subsystems.
- Include information in the medical record.

Develop and implement interventions in the context of family.
- Assess the key domains of family functioning.
- Identify relevant patterns of interaction.
- Identify strengths.
- Reframe problems.
- Enact healthier family patterns.

Family FIRST: The Family Is the Context of Care

The following mnemonic is designed for assessment and documentation of family functioning in the medical record.

F—Family defined
- Identify the names and ages of family members and others living in the same household.
- Ask about relationships among family members.
- Identify institutions involved.

I—Interaction patterns (observed by clinician or reported by patient/family)
- Among family members.
- Between the clinician and the family.
- Between family and the health-care system.

R—Resources and strengths (observed by clinician or reported by patient/family)
- Identify key resources, strengths, and coping skills (e.g., problem solving skills, strong support systems, community and/or faith-based resources).
- Assist patient/family in articulating their strengths.
- Provide your assessment of strengths to patient/family.

S—Stressors

Identify past and present stressors.
- Economic (employment, finances, government assistance, housing).
- Abuse history (physical, sexual, violence).
- Discrimination/racism.
- Physical and mental health status of family members.
- Identify major life transitions.

- Migration (adjustment/acculturation; English language literacy).
- Parenting.
- Separation/divorce.
- Serious illness/death

T—Time
- Identify short- and long-term goals and modify over time.
- Follow progress over time and identify areas of progress for family.

RESOURCES

American Academy of Family Physicians (AAFP): http://www.aafp.org/.

American Association for Marriage and Family Therapy (AAMFT): http://www.aamft.org/index_nm.asp.

Collaborative Family Healthcare Coalition (CFHA). A diverse group of health-care workers from primary and tertiary care settings who study, implement, and advocate for the collaborative family health-care paradigm: http://www.cfha.net/.

Family Process. A multidisciplinary international journal of research, training, and theoretical contributions in the family therapy: http://www.familyprocess.org/.

Families, Systems, & Health. A peer-reviewed journal of clinical research, training, and theoretical contributions with particular focus on collaborative family health care: http://www.apa.org/journals/fsh/edboard.html.

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Chapter 23

The Hidden Poor: Care of the Older Adult

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Objectives

- Identify the vulnerabilities of older adults.
- Review the coverage provided by Medicare and Medicaid.
- Outline strategies and resources available to assist in caring for vulnerable older adults.

INTRODUCTION

Adults over age 65 (older adults) are among the fastest growing age group in the United States, in part due to the "Baby Boomer" generation (adults born between 1946 and 1964) who started turning 65 in 2011. Between 2000 and 2010, the population aged 65 and over increased at a faster rate (15.1%) than the total US population (9.7%), resulting in 40.3 million adults over age 65, more than in any prior census.[1] By 2030, an estimated 70 million people, or 20% of the US population, will be over age 65, with the largest percentage increase among the old-old, those over age 85 years.[2]

The increasing size of the population of older adults is not unique to the United States. As infectious diseases become better treated, life expectancy, along with chronic disease burden in developing countries, is increasing. By 2050, there will be nearly 1.5 billion adults over age 65 worldwide.[3] Regional differences in the pace of aging exist; in sub-Saharan Africa, with 44% of the population under age 15, this pace is slower compared to Japan, China, and Europe where the median age in 2050 is expected to be nearly 50 years (versus 44 years in North America).[4,5]

Despite these variations, all countries will face the challenge of caring for an aging population. Around the year 2020, it is projected that the number of adults older than 65 years will outnumber children younger than 5 years worldwide.[3] The imbalance between the number of young people available to care for the increasing number of older adults is exemplified in China. As a result of the "one child per family" policy instituted in 1980, a single child will be challenged to care for aging parents and grandparents, thus increasing the need for development of other solutions, resources, and even facilities to care for older adults.[6]

The growing population of older adults presents unique challenges to providers, health-care systems, and caregivers in every country because of the vulnerabilities that often accompany aging. This chapter describes the vulnerabilities of older adults in the United States, although the concepts apply to any country, and discusses strategies to effectively care for this population (Box 23-1).

THE VULNERABILITIES OF OLDER ADULTS

Mrs. Jones is a 79-year-old African-American woman. She has type 2 diabetes, atrial fibrillation, high blood pressure, glaucoma, and osteoarthritis. Over the past year, she has lost 12 pounds and has fallen twice. On examination, her blood pressure is 190/83. Mrs. Jones is typical of many vulnerable older adults in the United States: she is a member of an ethnic/racial minority group with multiple comorbidities and significant health-care costs.

Box 23-1. Factors Increasing Vulnerability of Older Adults

- Multiple chronic medical illnesses.
- Economic insecurity.
- Mental health issues (e.g., cognitive impairment, depression, and occult substance use).
- Cultural and educational diversity.
- Frailty and dependency (including risk of elder abuse).

MULTIPLE CHRONIC ILLNESSES

Age is highly associated with increased burden of disease. Although 20% of all adults are affected by chronic illness, 80% of adults over age 65 report having at least one chronic condition and 52% have two or more conditions. In the United States, six of the seven leading causes of death in older adults are chronic illnesses: heart disease, cancer, chronic lower respiratory diseases, cerebrovascular diseases, Alzheimer's disease, and diabetes mellitus.[7] Chronic diseases decrease quality of life and function and can lead to institutionalization.

CULTURAL AND EDUCATIONAL DIVERSITY

In the 2010 US census, 80% of adults aged 65 years and older were non-Hispanic white. By 2050, it is estimated that this proportion will drop to 58%. The percent of minorities will increase: Hispanic older adults will increase from 7% to nearly 20%, Asian Americans from 3.3% to 8.5%, and African Americans from 8.3% in 2010 to 11.2% in 2050.[8] The increasing diversity of the older adult population is partly due to the aging immigrant population. In the 2010 census, more than one in eight US adults over age 65 were foreign born; this proportion will continue to grow.[9] Immigrants who migrate after age 60 are especially vulnerable as they are more likely to have low income, limited English language skills, lower educational levels, and little or no US work experience, which makes them ineligible for Medicare (see Chapter 29).[9]

Between 2000 and 2010, the percent of adults over age 75 with at least a high school education and bachelor's degree increased from 61% to 75% and from 13% to 19%, respectively. Despite the gains in educational attainment of this age group, the percentages remain lower compared to all adults over age 25, of whom 87% had attained at least a high school degree and 30% at least a Bachelor's degree. In addition, significant heterogeneity in educational levels in older adults exists among different racial groups. In 2010, 80% of non-Hispanic whites had at least a high school education, compared to 57% of African Americans and 39% of Hispanics.[10]

Formal education is no guarantee that the older adult will be able to adequately negotiate the health-care system. Many older adults have inadequate health literacy which may lead to difficulty reading prescription bottles or appointment slips, less understanding of more complex medical documents, higher health-care costs, and more likelihood of hospitalization (see Chapter 15). Difficulty seeing and hearing may compound these difficulties.

IMPACT OF POVERTY ON THE MORBIDITY AND MORTALITY OF OLDER ADULTS

> Mrs. Jones is widowed and lives alone in a subsidized senior apartment. She is unclear about the purpose of all her medications. "I have so many pills. Do I have to take them every day?" she asks. "They're so expensive." Her only insurance coverage is Medicare.

Because of Social Security and Medicare, older adults are perceived as economically secure. However, in 2010, 9% of older adults had annual incomes at or below the federal poverty level (FPL) of $10,458. Although this represents a substantial improvement from the 35% poverty rate observed in the 1950s, a further 28% of seniors are considered "low income," defined as having incomes less than 200% of the FPL.[11] In addition, poverty in older adults is not equally distributed across the population: the oldest old, women, those who live alone, the foreign born, and members of ethnic and racial minority groups are at higher risk for living in poverty.[11] Therefore, the typical poor older adult is a woman from a minority group who lives alone.

Poverty harms health. Because most adults over age 65 have health coverage through Medicare, it might be expected that they would be relatively protected from the negative health effects of poverty. However, this expectation is not supported by the literature.[12]

The poor have higher rates of mortality that are not fully understood. An inverse, linear relationship between income and mortality has been documented among Medicare beneficiaries.[13] In a study of socioeconomic status (SES) and mortality among older adults in four US communities, of the SES indicators studied, low income was the most consistently associated with increased mortality.[14] Another study of seniors who reported difficulty paying for food and medical bills at the time of discharge from an acute hospitalization found that those with the highest level of financial disability had a 25% higher 1-year mortality rate.[2]

Furthermore, older adults in the lowest income tertile (<$13,000) have been reported to have 60% higher rates of depression and twice the rate of functional limitation, and are less than half as likely to report good or very good health status.[15] The reasons for the health inequities observed in lower-income Medicare beneficiaries are complex (see Chapters 3 and 4).

HEALTH-CARE FINANCING FOR OLDER ADULTS: MEDICARE AND MEDICAID

Medicare is the primary insurer for older adults in the US. Over 95% of seniors are eligible and are covered, at least by Part A, which covers inpatient hospital and rehabilitation care. However, Medicare does not provide comprehensive coverage, as it excludes services such as eyeglasses, dentures, and long-term care. The Congressional Budget Office (CBO) estimates that Medicare covers only 45% of the health-care costs for the average beneficiary. In 2007, the median out-of-pocket annual spending for a Medicare beneficiary was $3138; 10% of Medicare beneficiaries spent more than $7800.[16] One in four beneficiaries spend 30% or more of their income on health care.[17]

To help cover the cost sharing under Medicare, most beneficiaries have supplemental coverage through private insurance, Medicaid, Medicare Advantage (MA or "Part C") or Medigap plans.[16] In 2014, 30% of Medicare beneficiaries were enrolled in an MA plan.[18] MA plans are offered by private companies that receive a fixed amount for each beneficiary covered under the MA plan. Beneficiaries enrolled in MA plans do not have traditional Medicare, as all services are provided by the MA plan, similar to a health maintenance organization. Some MA plans cover services not covered by traditional Medicare, such as dental care, hearing aids, and eyeglasses. Medigap coverage is sold by private companies with varying levels of coverage of costs such as copayments and deductibles. Medigap plans do not cover long-term care, dental care, eyeglasses, or hearing aids. Patients enrolled in Medigap have to be enrolled in traditional Medicare. In 2010, 23% of Medicare beneficiaries had a Medigap policy. About 40% of Medicare beneficiaries are also enrolled in Medicaid ("dual-eligibles"). Medicaid has traditionally provided coverage for poor older adults and has been the primary insurer for long-term care services, accounting for 30% of Medicaid expenditures in FY2011.

Despite Medicare coverage, lower-income older adults may still experience difficulties with access to care. In a survey of participants in the Cardiovascular Health Study, low-income respondents (defined as <$12,000 per year) were 2.6 times more likely to report a barrier to seeing a physician as those with incomes greater than $50,000.[19] Forty-seven percent of Medicare beneficiaries with incomes at or below 100% of the FPL reported difficulty with getting care or services, or difficulty paying medical bills.[20]

MEDICATION ISSUES AND THE MEDICARE PRESCRIPTION DRUG BENEFIT

Older adults who do not have coverage for or access to affordable medications often reduce their adherence to recommended medications because of cost concerns. Despite Medicare coverage, a low-income beneficiary may still pay 30% or more of his/her income in out-of-pocket health-care costs, with the bulk going toward prescription drugs. Medications that are not available in generic formulations, those that treat chronic illnesses that may not present with noticeable symptoms such as hypertension, and high-cost medications such as some antilipidemics are more likely to be reduced or stopped with predictable consequences for health. Mrs. Jones's question is not uncommon; seniors living on low-fixed incomes who lack drug coverage may self-ration or even forgo taking their medications.[21,22]

As part of the Medicare Prescription Drug Improvement and Modernization Act of 2003, a voluntary prescription drug benefit, Part D, was added and began in 2006. By the end of the first year of the plan, most enrolled beneficiaries without prior prescription coverage spent less on out-of-pocket prescription cost.[23] However, for some patients, the out-of-pocket costs remained high, as the Part D benefit has a built-in coverage gap. In 2014, the beneficiary first paid a $310 deductible and 25% of the next $2540 in drug costs. There was no further coverage until the out-of-pocket costs reached $4550 (i.e., the total spending on drugs reaches $6440). Catastrophic coverage began at this level and 95% of future drug costs were covered for the rest of the calendar year.[24] This gap in coverage has been referred to as the "doughnut hole." In 2007, 18.5% of Part D beneficiaries over age 65 reached the doughnut hole; only 11.6% of those reached the catastrophic coverage threshold.[25] The Affordable Care Act (ACA) provides a $250 rebate to Part D beneficiaries with any spending in the coverage gap and phases in coverage of the gap, reducing the copayment rate from 100% to 25% by 2020.[26]

Subsidies for lower-income adults are included in the Part D drug plan. Under Medicare Part D, beneficiaries at 135% of FPL or less have no premium or deductibles, pay a copayment of $2.55 for generic and $6.35 for brand name medications (in 2014), and have no doughnut hole.[27] The Kaiser Family Foundation estimates that beneficiaries who qualify for the low-income subsidy spend 83% less on out-of-pocket costs on prescription drugs (approximately $584) than they would have in the absence of a low-income subsidy Part D drug benefit.[28]

Table 23-1. Potential Cost Savings for Mrs. Jones

Benefit Level	Premium/Fee	Deductible	Copay	Monthly Drug Cost	Annual Total Cost	Annual Savings
No coverage[a]	None	None	None	$94	$1128	N/A
Standard Part D benefit (begins at 150% FPL)[b]	$32/month	$310/year	25% copay on next $2520 in costs after deductible: $630	$94	$899	$229
135–150% FPL	Sliding scale	$63	15% coinsurance up to $6455 total	$14	$169 + premium	$959–premium
<135% FPL	None	None	$2.55 per generic prescription $6.35 per brand prescription	$15–38	$180–457	$948–671

[a]Assumes patient is taking six prescription medications: atorvastatin, benazepril, metoprolol, timolol eye drops, warfarin sodium, and metformin at the lowest doses. Costs estimated from www.medicareadvocoacy.org and Emblem Health Medicare Rx calculator. All values on table rounded to the nearest dollar.
[b]FPL, federal poverty level defined in 2014 dollars: $11,670 per year for a single adult. Costs are as of the year 2014.

The low-income benefit phases out between 135% and 150% FPL. At 150% of FPL, the standard benefit applies. In October 2013, 11 million (about 30%) Part D beneficiaries were receiving low-income subsidies; an additional 2 million beneficiaries were eligible but not participating.

What does the prescription drug benefit mean to patients like Mrs. Jones? Assuming that she is taking the recommended medications, she is likely to be receiving at least six prescriptions (Table 23-1), If she is not eligible for any subsidy program, she will have an annual out-of-pocket cost of approximately $514, in addition to a monthly premium of $32.[27] If she is eligible for a low-income subsidy, then she would pay no monthly premium and her monthly medication cost would be approximately $15. Even without a low-income subsidy, she would save approximately 20% in out-of-pocket expense with the Part D plan, even when accounting for premium costs.

NUTRITIONAL ISSUES

Food security is defined as "access at all times to a nutritionally adequate, culturally compatible diet that is not obtained through emergency food programs." In 2011, about 8.4% of households with older adults experienced food insecurity.[29] Prevalence of food insecurity is higher in low-income older adults and minority groups.[30] Despite the existence of federal nutrition programs for poor older adults, only 40% of eligible households participate. Food insecurity in older adults is caused not only by financial constraints but also physical limitations, lack of social support, and poor medical and dental health. In 2010, 25% of men and women over age 65 reported having no natural teeth.[7] Dentures are expensive and not often covered by insurance. In turn, food insecurity contributes to poor physical and mental health, medication nonadherence, and poor chronic disease management. Mrs. Jones's weight loss may be related to medical or dental problems, but she may also be limiting her intake due to financial strain.

MENTAL HEALTH ISSUES

DEPRESSION

Data from the Health and Retirement Study in 2008 showed 11% of men and 16% of women reported clinically significant depressive symptoms.[7] Rates of depression are higher for older adults with medical comorbidities, with prevalence rates of depressive symptoms in hospitalized patients above 20% and nearly 45% in long-term care patients.[31,32]

Despite its high prevalence, depression in older adults is often unrecognized and untreated because the symptoms of depression can mimic medical illness or be attributed to medication effects or life events. In addition, seniors themselves may be reluctant to seek mental health treatment or report symptoms.

The costs (direct and indirect) associated with depression in the elderly are high. White men over age 85 have over four times the national rate for completed suicide: 45/100,000.[33] Depressed patients have impaired functioning, worsening of chronic medical conditions, and increased health-care costs.

COGNITIVE IMPAIRMENT

The prevalence of dementia in the United States is 3–11% in those aged 65 or older and 30–50% in those older than 85. Dementia is costly, with annual estimates exceeding $100 billion. It is also a common reason for institutionalization and in its early stages is associated with an increased incidence of depression. However, despite being common, dementia is underdiagnosed. About two-thirds of mild-to-moderate dementia is unrecognized by health-care providers.[34]

Cognitive impairment increases potential vulnerability in older adults due to its effect on executive tasks such as driving and medication and financial management. Patients with cognitive impairment may eventually

become dependent on others for these instrumental activities of daily living (IADL). For patients with limited social support and financial resources, oversight and assistance in these executive domains can be particularly challenging.

SUBSTANCE ABUSE IN OLDER ADULTS

The rates of substance abuse are lower in older adults compared with the general population. Nevertheless, it is a mistake to assume that older adults are immune to drug and alcohol abuse problems. A 2009 survey found a prevalence of binge drinking of 9.8% and of heavy drinking of 2.2% in adults over age 65.[35] The prevalence of alcohol abuse in hospitalized seniors may be as high as 20%[36] While only 1% of adults over age 65 reported illicit drug use in the past month,[35] nearly 25% of older adults use prescription psychoactive medications that have the potential to be misused or abused.[37] One study found up to 11% of women over age 60 misused prescription medications.[37] Screening instruments, such as the Michigan Alcoholism Screening Test-Geriatric version[38] and the CAGE questionnaire have been validated in geriatric populations (see Chapter 39). The possibility of substance abuse should be evaluated in patients with sudden decline in function, unexplained injuries, late life depression, cognitive impairment, or "failure to thrive."

FRAILTY AND DEPENDENCY

Although the majority of seniors are community dwelling and functionally independent, aging is associated with an increased need for assistance. Eight percent of those over age 65 living in the community reported three or more activities of daily living (ADL) limitations, 18% reported one to two ADL limitations, and 13% reported IADL limitations (examples of ADLs and IADLs are listed in Box 23-2).[7] Much of the caregiving for disabled seniors is provided informally in the community, often by a spouse or adult daughter. The 2009 National Alliance for Caregiving and AARP survey revealed that on average, informal caregivers provide 20.4 hours per week of care with 13% providing more than 40 hours per week, resulting in an estimated annual cost of over $300 billion for unpaid caregiver services.[39] Without informal caregiving, many disabled older adults would require formal paid services or institutionalization.

As increasing age is associated with increasing dependency, frail and disabled seniors are also at higher risk for victimization and abuse. Elder abuse remains under-recognized and under-reported, but in all states, health-care providers are required to report observed or suspected abuse of dependent adults. Types of abuse may include physical, sexual, psychological, mental, financial, and neglect, including self-neglect. Although there are no well-validated instruments for screening for elder abuse,[40] dependent older adults should be evaluated for abuse if there are unexplained injuries or delays in seeking medical care, changes in affect, evidence of malnutrition, or evidence of caregiver stress (Box 23-3).

Box 23-2. Activities of Daily Living (ADLs)

Basic ADLs	Instrumental ADLs
Dressing	Shopping
Eating	Housework
Ambulating	Accounting
Transfers	Food preparation
Toileting/continence	Transportation
Hygiene	Telephone/Technology use
	Taking medications

Box 23-3. Risk Assessment Questions for Elder Abuse[41]

- Has anyone at home ever hurt you?
- Has anyone ever touched you without your consent?
- Has anyone taken anything that was yours without asking?
- Has anyone ever scolded or threatened you?
- Have you signed any documents that you did not understand?
- Are you afraid of anyone at home?
- Are you alone a lot of the time?
- Has anyone ever failed to help you take care of yourself when you needed help?

From Aravanis SC, Adelman RD, Breckman R, et al. Diagnostic and treatment guidelines on elder abuse and neglect. Arch Fam Med 1993;2(4):371.

STRATEGIES FOR CARING FOR VULNERABLE OLDER ADULTS

Vulnerable older adults present multiple challenges to health-care providers (Box 23-4). As noted, they are medically and socially complex with chronic diseases that often cannot be cured. Often, the provider is caring for the caregivers in addition to the patient. It is also a truism of geriatric medicine that the mortality rate is unfailingly 100% with a significant proportion of seniors relinquishing their ability to have meaningful interactions some time before death. Given these challenges, many

Box 23-4. Common Pitfalls in Caring for Older Adults

- Understanding health-care benefits is difficult for patients and providers.
- Benefits for seniors are not comprehensive.
- Lack of appropriate nutrition is common.
- Mental illness, substance use, and dementia go undetected.
- Many barriers to active participation in health care, including physical and mental limitations, culture, literacy, and education are particularly prominent in older adults.
- Care complexity and limited reimbursement reduce the numbers of providers willing to care for older adults.

providers feel ill equipped to care for these patients, lacking the experience, knowledge, or practice infrastructure needed to coordinate the care required for complex older adults. The following strategies provide suggestions for a patient-centered approach to caring for medically and socially complex older adults.

REFRAMING PRACTICE

Geriatric Syndromes and Functional Assessment

If the purpose of the medical visit can be reframed to maximizing function as opposed to "curing" disease, the outcome can be satisfying for both the health-care provider and the patient, with improved quality of life for the patient and caregiver. Many older patients present with multiple signs and symptoms related to several organ systems and impaired functioning in multiple domains, and defy single unifying diagnoses. These conditions have been classified as geriatric syndromes and include commonly encountered problems such as dizziness, falls, and incontinence. Naming a condition a "geriatric syndrome" does not imply that the provider no longer has an obligation to seek out underlying pathologic or potentially reversible disease states. It simply emphasizes the equal importance of assessing the condition's impact on the patient's level of function and mitigating existing risk factors in order to maximize function. Among others, these risks can include polypharmacy, environmental obstacles, and sensory impairments.

In assessing function, it can be useful to define the level of the functional impairment. Traditionally, function has been described in terms of ability to perform activities of daily living (ADLs), categorized as those requiring personal care assistance and those that are necessary to live totally independently (IADL). A senior's baseline functional status can be used to guide treatment, for example, the prescription of adaptive devices. Changes in function can be followed over time and may alert a provider to decline requiring a higher level of care, and to caregiver stress (see Box 23-2).

The numerous functional domains that can be assessed—continence, falls and immobility, hearing and vision, depression and dementia, abuse, polypharmacy, and nutrition, to name a few—may seem daunting within the confines of the "15-minute" visit, but there are simple tools that can help the primary care provider effectively screen geriatric patients. Indeed, these tools do not have to be administered by the provider but can be delegated to other office staff. The authors offer one tool, originally developed and validated by Moore and Siu[42] and later modified by Lachs[43a] and Johnston (see "Core Competency").

Approach to Polypharmacy

Nearly 20% of community-dwelling adults aged 65 and over take 10 or more medications, which can easily be reached if a provider were to follow all of the disease-specific guidelines. In a hypothetical patient with five chronic medical problems, the medication list would contain 12 different medications![43] Polypharmacy can be a particularly challenging issue to address in a short visit but one that can have profound impact on an older adults function, quality of life, financial health (as in Mrs. Jones's case), and risk for adverse outcomes such as functional decline and death.

Performing periodic "brown bag" reviews in which patients bring all prescription and over-the-counter medication bottles into the office can be helpful to not only assess adherence but also ensure there are no medication–medication interactions or medication–disease interactions and that the medication regimen supports the patient's health goals. Potentially inappropriate medications which can contribute to adverse events or functional decline can also be discovered during this review. In one study of a brown bag review, in 12% of patients, medication problems were identified that could have resulted in a hospital admission.[44]

Focus on Goals

The typical primary care patient presents for episodic acute care, chronic disease management, and preventive services. As patients age, the variety and number of recommended interventions for both health maintenance and disease management can become quite complex and intimidating to both providers and patients. Although Americans are living longer, research to guide evidence-based practice, particularly for the "old-old" (over 85), is lacking. What then is the conscientious provider to do?

Regarding preventive services, one approach is to recognize the effect of life expectancy on potential benefit. In general, the patient's life expectancy should be at least

Table 23-2. Average Life Expectancy by Age/Gender (for European Americans)

Age	Gender	50th Percentile	25th to 75th Percentile
70	Female	15.7 years	9.5–21.3
	Male	12.4 years	6.7–18
75	Female	11.9 years	6.8–17
	Male	9.3 years	4.9–14.2
85	Female	5.9 years	2.9–9.6
	Male	4.7	2.2–7.9

Source: Walter LC, Covinsky KE. Cancer screening in elderly patients: A framework for individualized decision making. JAMA 2001;285:2750-2756.

5 years in order to benefit from many preventive screening tests. A healthy 75-year-old woman would be expected to live another 12 years and, thus, should be considered a reasonable candidate for interventions such as colon cancer screening. However, if she had other comorbidities, such as moderately severe congestive heart failure or emphysema, it would be unlikely that she would live long enough to benefit from screening and should not be subjected to testing (see Table 23-2).[45]

However, even for healthy older adults, a principal consideration should be the patient's values and goals for the remainder of life. A shared decision-making approach should be used. It is important for the health-care provider to elicit and document the patient's views regarding future goals and what constitutes an acceptable quality of life. At times, this requires the involvement of the family or the caregivers, particularly in cultures for which decision making is a family-shared responsibility. Knowledge of the patient's goals will inform decision making about screening and diagnostic tests and treatments. Also, near the end of life, understanding the patient's goals of care is ultimately more important than making a determination about cardiopulmonary resuscitation or intubation.

RESOURCES TO ASSIST IN THE CARE OF THE VULNERABLE OLDER ADULT

> Mrs. Jones suffers a stroke and is admitted to the hospital. Her nephew is willing to help, but is concerned he won't be able to afford the kind of care his aunt will need. The hospital social worker helps Mrs. Jones apply for Medicaid and schedules a home safety evaluation. She is referred for Medicaid Waiver care management. In conjunction with her primary care physician, the care manager arranges for Mrs. Jones to attend an adult day health-care program where she receives social support, meals, and physical therapy.

The patient and family may look to the primary care provider for assistance with issues that are not traditionally medical in nature, but that may have greater impact on health and quality of life than many medical interventions. As health-care providers care for increasingly medically complex patients with fewer available resources and less time, it is important to incorporate a team approach to care for older adults, particularly those with complex medical and psychosocial issues. As poor seniors are at risk for worse health outcomes, existing resources that can assist health-care providers in caring for their vulnerable older patients are reviewed here.

Care Management Programs

Geriatric care management is a relatively new field in which providers (often nurses or social workers) coordinate and oversee health and personal care for older adults. Private geriatric care management is unregulated, costly, and not covered by Medicare or insurance. However, some states have opted to use Medicaid dollars to fund targeted case management for some older adult populations, a program termed "Medicaid Waiver." Community-based Medicaid Waiver services vary by state, but can include case management, homemaker, home health aide, personal care, adult day health services, and respite care.[46] The ACA created an optional Medicaid state plan benefit for states to establish "health homes" to coordinate care for Medicaid patients with chronic conditions. The health homes focus on provision of quality, whole-person-centered care that coordinates all primary, acute, mental health, and long-term services.[47]

Nutrition Programs

Congregate and home-delivered meals are available through Title III–funded nutrition programs that target low-income and disabled seniors. There may be a small copayment or requested donation for each meal, although most elderly nutrition programs will not turn anyone away for inability to pay, but there is generally a waiting list for home-delivered meals. The Administration on Aging estimates that in FY2010, 145.4 million meals were home delivered to over 800,000 individuals and congregate nutrition services provided 96.4 million meals to over 1.7 million older adults.[48] Government supplemental nutrition assistance programs (formerly named "food stamps") are also available to adults over age 60 with a net income of 100% of the FPL or less but is an under-used resource.

Program of All-Inclusive Care for the Elderly Programs

Program of all-inclusive care for the elderly (PACE) targets adults aged 55 or older covered under Medicare and Medicaid Waiver programs; there is limited access for those with higher incomes. PACE provides inclusive care for enrolled patients who would otherwise qualify for nursing home level of care. Patients attend medically supervised, structured programs daily but return home at night. They also may receive in-home personal care services as well as respite care if needed.[49] Because PACEs are capitated, the enrolled patients must agree to have all of their care assumed by the PACE and must leave their current primary care providers. As of April 2014, there were 104 PACEs in 31 states.[50]

Pharmaceutical Assistance Programs

Nearly 75 pharmaceutical companies offer free or reduced cost medications to patients who meet the income criteria. Fifty-three percent of the 200 most commonly prescribed medications are available through pharmaceutical assistance programs (PAPs).[51] The paperwork associated with each program can be cumbersome, requiring a significant degree of literacy and the willingness to disclose personal income information. Several Web sites exist, some sponsored by the pharmaceutical industry, that assist patients in applying for these programs. Some sites distribute the information to multiple companies after the completion of one electronic form. This may expand access to programs for patients who use the Internet. One pharmacist-led intervention using PAPs showed reduced out-of-pocket medication cost for low-income seniors.[52]

Community Resources

Many charitable and professional organizations and governmental agencies are dedicated to providing different types of care to elderly persons. Table 23-3 provides a partial list of community resources available to older adults. The Eldercare Locator, a public service of the US Administration on Aging, can help older adults and their families find local providers of personal nonmedical care in their area (see "Resources" section).

Table 23-3. Resources for Seniors

Resource	Services Available	Cost/Coverage
Senior centers	Activities, congregate meals	Free or small donation for meals ($2–$5)
Adult day health centers	Skilled nursing, PT/OT, social activities, meals	Medicaid, self-pay, some with sliding scale
Home health aide	Personal care	$10+/hour, self-pay, Medicaid, Medicare if linked to skilled need
Respite care	Nursing home level care	Self-pay, limited Medicaid, Veterans Affairs benefits, Medicare if linked to hospice
Meals on wheels	Delivered meals	$3–$5/meal "donation"
Transportation	Van/taxi service	Self-pay, may be locally subsidized
Support groups	Peer support	Free
Friendly visitors	Volunteer social visits	Free

CONCLUSION

Despite the financial gains achieved by older Americans in the last century, many continue to face significant health-care costs that can lead to financial insecurity. As the global population continues to age, increased stress will be placed on health-care systems that may not be adequately resourced or fiscally prepared to care for a substantially older and vulnerable population. In order to meet the needs of seniors who live in poverty, health-care providers will need to be aware of the multidisciplinary resources that exist in their communities that can assist them in caring for this especially vulnerable population of older adults.

Caring for Older Adults

- Use a patient- and family-centered approach.
- Focus on function and on goals.
- Involve caregivers.
- Ask about geriatric syndromes, e.g., falls, incontinence, dementia, depression.
- Use available assessment tools.
- Use remaining life expectancy to guide prevention efforts.
- Get help! Caring for complex older adults requires an interdisciplinary, team approach.
- Connect patients with community-based resources.

The Simple Geriatric Screen

History items	Action
Have you had any falls in the last year?	• Gait assessment • Osteoporosis and injury risk assess • Home evaluation • Physical therapy
Do you have trouble with stairs, lighting, bathroom, or other home hazards?	• Home evaluation • Physical therapy

Do you have a problem with urine leaks or accidents?	• Rule out reversible causes • History (stress, urge) • Physical examination • Post-void residual
Over the past month, have you often been bothered by feeling sad, depressed, or hopeless? During the past month, have you often been bothered by little interest or pleasure in doing things?	• GDS or other depression assessment
Do you ever feel unsafe where you live? Does anyone threaten you or hurt you?	• Explore further • Social work • Adult protective services
Review medications that patient brought in: • Confusion about medications • >5 Medications • Does not bring in • Also ask about herbs, vitamins, supplements, and nonprescription medications	• Consider simplification • Medi-set or other aid • Consider home visit • "Brown bag" review
Is pain a problem for you?	• Evaluate

Do you have any problems with any of the following areas? Who assists? Do you use any devices? (for "yes" answers, consider causes, social services, and/or home evaluation/ physical or occupational therapy (PT/OT)

Doing strenuous activities such as fast walking/bicycling?	Yes___	No___
Cooking	Yes___	No___
Shopping	Yes___	No___
Doing heavy housework such as washing windows	Yes___	No___
Doing laundry	Yes___	No___
Getting to a place beyond walking distance by driving or taking a bus	Yes___	No___
Managing finances	Yes___	No___
Getting out of bed/ transfer	Yes___	No___
Getting dressed	Yes___	No___
Toilet	Yes___	No___
Eating	Yes___	No___
Walking	Yes___	No___
Bathing (sponge bath, tub, or shower)	Yes___	No___

Physical Examination Items (may be performed by nursing staff in some settings)	Abnormal	Action
Weight/BMI And ask "have you lost weight? If so, how much?	BMI <21 Loss of 5% since last visit or 10% over 1 year	Alert provider • Nutrition evaluation • Consider medical, dental, social work evaluation
Jaeger Card or Snellen eye chart; test each eye (with glasses)	Cannot see 20/40	Alert provider or refer
Whisper short sentence at 6–12 in. (out of visual view) or audioscopy	Unable to hear	• Cerumen check • Retest/refer • Hearing handicap inventory
Name three objects/ re-ask in 5 minutes Clock draw test	Misses any or unable	• MMSE or other screening test
"Rise from your chair (do not use arms to get up), walk 10 ft, turn, walk back to the chair, and sit down."	Observed problem or unable to complete in <15 s	• Further gait and neurologic examination • Home evaluation and PT
"Touch the back of your head with your hands." "Pick up the pencil." (Remember to ask about the three items!)	Unable to do either	Further examination, consider OT
Other areas of concern: caregiver stress, alcohol, social isolation, exercise, driving, advance directives, and health care wishes.		

Source: Modified by C. Bree Johnston from: Moore AA, Siu AL. Screening for common problems in ambulatory elderly: Clinical confirmation of a screening instrument. Am J Med 1996;100:438-443. Adapted and reproduced with permission from C. Bree Johnston.

DISCUSSION QUESTIONS

1. Using a patient or family member, calculate the cost of the Medicare Part D drug benefit. Will the drug benefit result in savings?
2. Describe the resources that are available in your community for elders like Mrs. Jones.
3. If Mrs. Jones was not eligible for Medicaid, what other resources would be available?

RESOURCES

The Web site of the American Association of Retired Persons; this site contains consumer-directed information on general topics related to aging: http://www.aarp.org.

Alzheimer's Association: 1-800-272-3900 (www.alz.org).

The Family Caregiver Alliance: 1-800-445-8106 (www.caregiver.org).

The US Administration on Aging maintains a comprehensive Web site with information on resources of interest to seniors, their families/caregivers, and health professionals. For specific information on local resources, the Web site provides links to state and area aging agencies as well as contact information for the nationwide Eldercare Locator service: www.AOA.gov.

Web site maintained by the American Elder Care Research Organization. Provides general information on costs of senior care and links to search for specific care services: https://www.payingforseniorcare.com.

National Adult Day Services Association. Web site contains general information on adult day programs and tips for caregivers on choosing a program: http://nadsa.org.

Web site of special projects of the Administration on Aging. This page contains links to resources and information on global aging: http://www.aoa.acl.gov/AoA_Programs/Special_Projects/Global_Aging/resources.aspx.

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Chapter 24

Care of the Dying Patient

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Objectives

- Identify unique burdens of vulnerable persons at the end of life.
- Identify communication barriers to quality care for the dying.
- Discuss challenges to end-of-life decision making.
- Identify models of health-care delivery for dying patients.
- Summarize practice guidelines and suggest other strategies to improve care of the dying patient.

INTRODUCTION

Mr. Smith, a 74-year-old man with an 8th grade education, presents to the emergency department (ED) with profound shortness of breath and generalized weakness. In the ED, he complains of fatigue and significant weight loss over the past 4 months. He does not have a primary care provider and his father, who was his last living relative, died about 6 months ago. He has a small circle of friends, and although he currently has a stable living situation in a boarding house, he has had bouts of homelessness in the past. His past medical history is significant only for schizophrenia.

He is found to have a right-sided pleural effusion and lytic lesions of several ribs. He is informed of the findings and the need to rule out a serious life-threatening condition such as metastatic cancer. He refuses admission to the hospital, further workup, and declines referral or further discussion. He leaves the ED against medical advice.

Facing one's own mortality is one of life's greatest challenges, one that makes all people vulnerable. Despite the successes of the hospice movement and advances in the field of palliative care, physical and existential sufferings are still common at the end of life. At the lowest estimates, every year about 20 million people worldwide need end-of-life palliative care, including over a million children.[1] Even in North America, Europe, and Australia, with developed palliative care programs, there are many unmet needs.[1] Access to palliative care is considered by many to be a basic human right.[2] The UN Committee on Economic, Social and Cultural Rights stresses the importance of providing "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."[3]

The palliative care movement also considers dying pain free and with dignity a basic human right. Human rights groups see denying access to pain relief to the dying as tantamount to torture. For people marginalized by social or economic circumstances, illiteracy, or cultural or language barriers, suffering may be compounded by additional burdens. As a result, end-of-life care goals and priorities for marginalized patients extend beyond clinical concerns and may require providers to act as advocates on behalf of social and economic equity.[4-6] This chapter identifies key issues for the dying patient, focusing

on difficulties encountered in medical discussions and in decision making in the face of death in marginalized patients in the United States. Various end-of-life health-care delivery models are summarized along with practice guidelines and other strategies that may improve the quality of life for dying patients.

CHALLENGES IN THE CARE OF THE DYING PATIENT

DEFINING A GOOD DEATH IN THE CONTEXT OF SOCIAL INEQUITIES

How does one define a "good death" for the person whose capabilities in life have been constrained by disadvantage, or whose imminent death may result, in whole or in part, from societal factors responsible for socioeconomic inequalities or racial or ethnic-based inequities? Life expectancy among vulnerable persons is generally lower than their more privileged counterparts.[7] Their deaths are often premature, occur at younger ages, and are associated with a markedly diminished quality of life.

Many factors, including religious or spiritual beliefs and cultural heritage, determine how one thinks about death and dying, advance directives, hospice, and the concept of a good death. For example, not all persons value dying at home or have the support to do so. Homelessness in particular rules out this option. In addition to lack of housing, homeless persons are challenged by having no safe place to store medication and by unreliable transportation to follow up with health-care providers. Paying particular attention to a patient's conception of a "good death" and the support needed to achieve it can in itself relieve suffering. Avoiding the temptation to engage in stereotyping by social, racial, ethnic, or cultural categories and maintaining a focus on the quality of care offered to each individual or family (Table 24-1) is a first step to easing suffering at the end of life.

Table 24-1. Common Issues to Remember When Dealing with Dying Patients and Their Families

- Compassionate, respectful communication ensures patient and family dignity throughout the dying process
- Processes of care should take into consideration patient and family's cultural and religious/spiritual values, which are most salient under the stresses of life-threatening illnesses.
- Homeless patients who may be estranged from family may still desire compassionate companionship at the end of life.
- Everyone deserves to experience the end of life free from pain and other symptom burdens.
- Palliative care teams are often able to provide comprehensive interdisciplinary care that can address the needs of vulnerable patients and families.

DIFFICULTIES IN DISCUSSING DEATH AND DYING

> Mr. Smith returns to the ED with pronounced weakness and an additional 5-pound weight loss. He complains of a very poor appetite and difficulty climbing the stairs. His long and difficult history with mental health institutions makes him wary of hospitals and medical personnel, but he reluctantly allows admission to the hospital because he feels so poorly. When he is asked about his resuscitation preferences, he requests that full resuscitation measures be instituted if needed.
>
> The workup reveals adenocarcinoma of the lung. The medical oncologist tells him his diagnosis and recommends further tests. Mr. Smith refuses, expressing some suspicion of the diagnosis of cancer.

In the case of Mr. Smith, and generally for all patients at risk for death, clear, ongoing, intelligible, and compassionate communication is essential. When discussing difficult diagnoses and prognosis with patients and families, it is critical to attend to timing and setting. Additionally, the ability to exchange information is influenced by native language, cultural backgrounds, education, and literacy, as well as by trust, continuity, and the relationship between patient and providers. The emotional and psychological nature of conversations about serious illness and death may interfere with any patients' ability to hear, understand, or remember conversations with health-care providers.

COMMUNICATION BARRIERS

Obvious communication barriers occur when patients and providers do not share the same native tongue or professional language (see Chapter 31). Highly technical medical vocabulary may be foreign to patients. Less evident, but perhaps more problematic, are cases in which a patient's primary language is a dialect of a shared native tongue, such as black vernacular English or Creole. In such cases, the need for translation may not be apparent even though the parties may not fully comprehend each other.

Literacy, which entails not only the skill to read or write in a primary language well enough to function in society but also the ability to understand health information provided orally, including instructions for procedures or therapies (see Chapter 15) also has a profound effect on communication between patients and health-care providers. Health literacy requires the negotiation of explanatory models, and some patients or surrogate decision makers, including those with Durable Power of Attorney authority, may not understand basic physiologic processes well enough to comprehend medical explanations, even when such explanations are presented in lay terms.

TERMINAL ILLNESS AND DISCUSSIONS OF PROGNOSIS

Discussing death and delivering bad news is not an easy task, even for the seasoned provider. It may require one to confront one's own mortality or unresolved grief from a personal loss. Communicating difficult news may be particularly problematic for providers who see death not as an inevitable part of life but rather as the failure of the limits of medical skill or technology. As a coping strategy, they may overuse technical language, defer the conversation, or, worse, avoid the patient altogether.

Providers who care for large numbers of vulnerable patients may come to view death as a failure of social responsibility or they may worry that communicating bad news may diminish hope. The desire to maintain hope may explain the general tendency for physicians[8-11] to overestimate prognosis by a factor of 3–5. The consequences of these overestimates are serious and may, in part, account for late referrals to hospice when patients have only hours to days, rather than weeks to months, to benefit from quality palliative care.

Do we know what and how much patients want to know about their prognosis? Few studies have identified patient preferences regarding information sharing before receiving a terminal diagnosis.[12] The question often presumes that patients already know that they have a terminal or potentially fatal condition and that they wish to get a realistic picture of the future. This may be based on a hidden assumption about an "ideal" patient, one who shares the Western ethical precepts of truth-telling and respect for patient autonomy.[13] Cultural differences influence preferences about information sharing and the willingness to discuss prognosis. For some, discussing death may be tantamount to wishing it upon the patient. Some families prefer that the patient never know of their condition, and that decision making be carried out by a proxy.[14,15] These values and preferences may conflict with those of the provider or others involved in care of the dying patient.

The ability for a patient to hear, understand, and accept difficult news may be influenced by patient trust in the provider or the health-care system. In the case of Mr. Smith, the first intimation of a poor prognosis came early during his admission when asked about his resuscitation preferences by a hurried health-care provider. Later, receiving the news of his cancer diagnosis from another physician, one with whom he had no prior relationship, increased his suspicions. Had he received the information in a longstanding primary care relationship, his acceptance and understanding might have been different. For some vulnerable persons, access to care is limited, making continuity of care at the level of health services or of providers an unrealistic option and uncoordinated care in resource-constrained settings more common. In the absence of long-term continuity, compassionate communication is all the more critical.

DELIVERING BAD NEWS

Clinicians can learn to deliver bad news in a manner that can aid in patients' acceptance and facilitate their participation in health-care decisions. Advance preparation is a key prerequisite. Medical facts should be confirmed prior to having the discussion and the providers must be prepared to discuss them in simple language. Every effort should be made to invite not only medical staff but also family or others important to the patient. A six-step protocol for delivering bad news, based on the work of oncologist Robert Buckman, has been widely adapted and endorsed[16] (see "Core Competency"). By practicing the following steps in advance, the provider can increase his or her own comfort level before facing a difficult situation and, perhaps most importantly, ensure that they will not deliver unwanted information.

FAMILY MEETINGS

Far too often, when medical information is shared, it is misunderstood, misinterpreted, and confusing to a patient. When bad news is delivered, even in the most clear and compassionate manner possible, the patient may recall very little of what was presented, and what they do remember is often inaccurate. In a time of great shock, it is important to have another person present to participate in the discussion, take notes, and ask questions. Ideally, this person would be the surrogate decision maker, if one has already been established.

For those who wish to have multiple family members present and involved in the decision making, then a family meeting would be most useful. What is especially useful in the Buckman protocol described earlier is its adaptability for use in a family setting. It can provide structure to the meeting in a way that establishes order and allows inclusion of all those present. Beginning the meeting with a question probing understanding of the diagnosis and prognosis allows the team to hear from the patient and family in their own words what they understand as the medical problem. Having the patient or family speak first not only shows respect but also establishes the team's listening role, which is critical in providing care. It also allows the team to deliver the news in a framework informed by the patient's understanding. Whenever possible and appropriate, it is important to include other members of the interdisciplinary health-care team. Chaplaincy and social work support can be of tremendous help during the meeting and will help the team to recognize needs that may impact the course of future care.

DECISION MAKING AT THE END OF LIFE

> Treatment options are discussed with Mr. Smith. Although he demonstrates capacity to understand the information given, he is adamant that he does not want to pursue any further treatment. Once his breathing is better, he just wants to go home. A medical social worker encourages him to tell his support network about his illness, but he is reluctant to involve his friends.

A central tenet in medical practice is that individuals have the right to autonomous choice in receiving or refusing medical care. This presumes that such choices are intentional, informed, and free of controlling influences.[17] However, a range of circumstances that disproportionately affect the vulnerable (e.g., language, education, or literacy barriers; mental disorders; economic constraints) may undermine the ability of providers to understand and assure that the choices are clearly and freely made. Ideally, end-of-life decisions should be guided by a person's values and wishes, and it is important for health-care providers to learn what these are. Chaplaincy assessment can be invaluable in this regard.

Various hospices, palliative care organizations, and providers promote the use of values history forms (http://c.ymcdn.com/sites/www.hospicefed.org/resource/resmgr/hpcfm_pdf_doc/valueshistoryform.pdf) that provide a useful set of exploratory questions such as the following: "What goals do you have for the future?" "How satisfied are you with what you have achieved in your life?" or "What do you fear most?"[18] Written for a more general audience, some of the questions in these forms are oriented to life conditions that may not be relevant to the poor, the homeless, refugees, or other vulnerable persons. In these circumstances, rather than asking generally about future goals and past achievements, one might inquire more specifically, "What do you hope for in the near future in regard to living situation, physical comfort, medical conditions, relationships, etc.?" or "Where do you find satisfaction?"

An additional ideal is that goals of care and values be documented in a written advance directive, a living will, POLST (Physician's Order for Life Sustaining Treatment) (http://www.polst.org/), or other formal or legal document. This helps ensure that if patients are unable to speak for themselves, their autonomous wishes nonetheless will be known and carried out. Although Mr. Smith demonstrated capacity to understand the information, should his disease progress, his capacity may diminish. Persons who are deemed unable or incapacitated to make informed end-of-life decisions need to have a surrogate decision maker for them.

In the absence of an advance directive, designated decision makers could be those closest to the patient. When suitable contacts, family, or legal guardians are available, they may be asked to provide a substituted judgment—one that is based on the wishes of the patient (and not on the surrogate's wishes). In some cases, there may be no one who can speak for the patient. Social isolation is common among vulnerable patients with serious life-limiting conditions. A medical social worker may investigate the patient's support system to identify possible surrogates. Physicians, hospital ethics committees, hospital surrogate decision teams, or courts may need to serve in that role. Without knowledge of the person's values and wishes, quality-of-life criteria have been applied to decisions based on what is in the best interest of the patient. These determinations can be challenging, at best. For example, consider the case of a young man found unconscious and badly beaten, and without any form of identification. An emergency room evaluation reveals severe nonsurgical brain injury; he is stabilized and admitted to intensive care. Two weeks later, he remains comatose. He also remains a "John Doe" with no known identifiable family members, friends, or social network. What decisions should be made about his care, particularly if his neurologic condition fails to improve and a diagnosis of persistent vegetative state is made? Who should make these decisions and whose values should guide the decision-making process on his behalf?

Values become a contestable arena for vulnerable patients at the end of life. This is particularly true for decisions involving medically futile interventions, often defined as life-sustaining interventions that lack medical efficacy and lead to little or zero chance of survival.[19-21] Providers should not be required to provide services that offer no meaningful benefit to the patient. However, complex decisions require the inclusion of the patient's personal values in defining what is deemed meaningful. Ultimate decisions regarding the withdrawal or withholding of medically futile interventions may be ethically defensible but still subject to legal challenge. Furthermore, larger societal forces (e.g., poverty, war, and trauma) may have contributed to the conditions that directly or indirectly led to death in the first place. In some cases, dying patients who have lacked access to health care may view discussion of withdrawal or withholding of care a further example of social injustice. In addition to principles of beneficence and nonmaleficence then, other ethical principles—most notably justice and equity—may need to be considered in such end-of-life decisions.

HEALTH SYSTEM ISSUES

> While hospitalized, a referral is made for Mr. Smith to be seen by the palliative care consult team to address pain and other symptom management and to help him identify his goals of care. He continues to request full resuscitation if needed but refuses to discuss any other end-of-life care options such as

hospice. He only wants to return home. To accommodate his wishes, the social worker on the team assists in planning Mr. Smith's discharge. In light of his debilitated state, several in-home support services are planned. Aware of his increasing dependence on others for his daily needs and his difficulties in getting to any follow-up medical appointments, the social worker recommends he enroll in a home-based advanced illness management (AIM) program as well as a "meals-on-wheels" food delivery service. He declines the AIM referral but welcomes the meal supports.

PALLIATIVE CARE SERVICES

Quality palliative care—the total active medical, psychological, social, and spiritual care of patients who have received a diagnosis of a serious, life-threatening illness—requires a different health-care system than the acute-care conventional model dominant in most developed nations. Multiple models of palliative care have emerged in the past decade, and palliative care provisions vary by hospital, ranging from consultative services to fully staffed wards. As the benefits of palliative care become clearer, institutional support has increased, although funding remains a challenge.[22] In the United States, expanded health coverage with the Affordability Care Act has created the potential for increasing access to end-of-life care services.

Palliative Care

Management of advanced illness includes attention to multiple aspects of a person's well-being. Palliative Care, well established in the United Kingdom since the 1960s and a recognized medical subspecialty in the United States since 2006, focuses on the care of patients with advanced illness with the goal of improving pain and symptom control and enhancing quality of life in all aspects of a person's life (i.e., physical, emotional, psychosocial, and spiritual). Although its patient-centered, goal-directed approach to care is similar to that of hospice, palliative care is often provided at the same time as curative or disease-modifying treatment. This can be the best option for patients like Mr. Smith who continue to request full intervention.

Palliative care is best offered through an interdisciplinary team composed of physicians, nurse practitioners, registered nurses, chaplains, social workers, and other appropriate staff. Collaboration and teamwork with other disciplines can maximize resources and facilities, encourage innovation, and increase professional satisfaction.[23] Successful interdisciplinary teams require planning and effort, yet skills for working across disciplines are not a part of usual health-care training (see "Core Competency"). In addition, it is essential to foster and maintain ongoing communication and collaboration regarding goals of care with other providers who may not be part of the formal interdisciplinary palliative care team but are nonetheless involved with the patient's care.

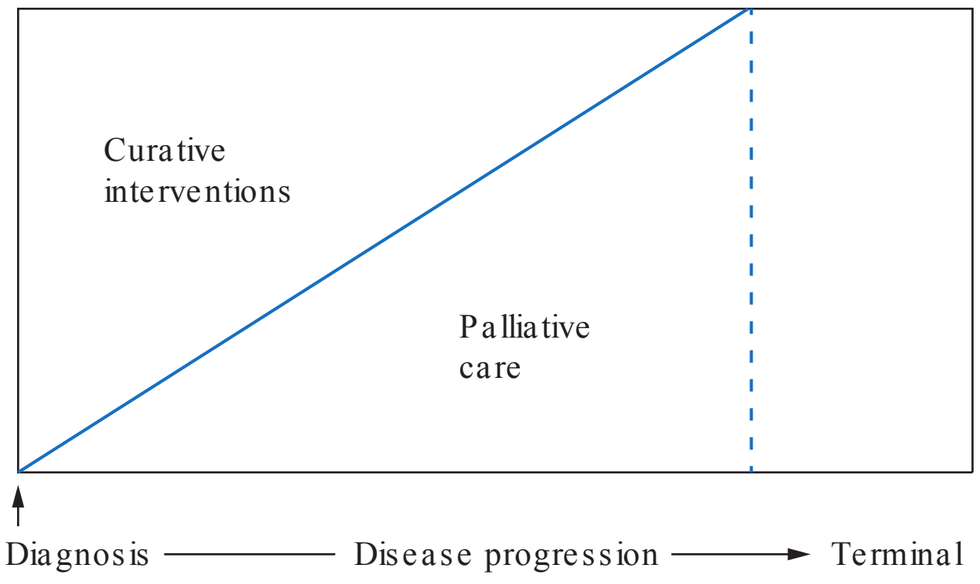


Figure 24-1. Continuum of care. (Adapted from Lynn J. Living long in fragile health: The new demographics shape end of life care. Hastings Cent Rep 2005; Spec No:S14-S18.)

Palliative care is most effective when aiding in the management of symptoms and challenges brought on by serious illness or in the transition toward the end of life as the disease progresses and treatment options become more limited. Moreover, as the benefits of palliative care become clearer, efforts are being made to expand its tenets of value-oriented care and enhancing quality of life to long-term chronic disease care long before death is imminent. Figure 24-1 shows the ideal delivery of care offered at the time of diagnosis with increasing palliation over the course of disease progression as curative interventions become less effective. As the field of palliative care grows, there will be continued innovations, including outpatient palliative care services that will move this care further upstream.

Clinical Practice Guidelines for Quality Palliative Care

Care of the dying requires a multidisciplinary team approach to address the physical, psychosocial, spiritual, and practical needs of patients. A consortium of US hospice and palliative care organizations partnered to develop the National Consensus Project (http://nationalconsensusproject.org/) and establish evidence-based clinical practice guidelines for quality multidisciplinary care.[24,25] These guidelines address care issues in the following domains: structures and processes; physical care; psychological and psychiatric care; social aspects; spiritual, religious, and existential issues; cultural aspects; care of the imminently dying patient; and ethical and legal aspects of care (see "Core Competency").

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life

for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is realized through management of pain and symptoms, psychosocial distress, spiritual issues, and practical needs throughout the continuum of care. However, the physical and existential suffering associated with serious and eventually fatal conditions are only one part of the overwhelming stressors with which the vulnerable patient must contend. The guidelines also emphasize the need to share information with the patient and family about changing conditions and treatment options.

Language and literacy barriers may make information exchange particularly challenging. Although the gold standard of palliative care strives to ensure genuine coordination and continuity of care across settings, health care for the disenfranchised may be fragmented or delivered in emergency rooms or other clinical settings where time and resources are constrained. Lastly, the guidelines emphasize the value of preparing both the patient and family for the dying process, and for death, when it can be anticipated. However, a disproportionate number of vulnerable persons suffer sudden death, precluding the ability to prepare. These examples illustrate the stark contrast between the goals of palliative care and the realities of the dying vulnerable.

HOSPICE CARE SERVICES

Hospice care is designed to give supportive care to people in the final phase of a terminal illness and focuses on comfort and quality of life, rather than cure. It can be delivered at home or as an inpatient. It was the first comprehensive model to address the multidisciplinary needs of the dying in a coordinated fashion.

Although funding in the United States through the Medicare program has included hospice coverage provisions since 1983, certain requirements can create barriers to its use. For example, curative treatments or transfers to the hospital are not covered and eligibility requires a prognosis of likely death within 6 months. New demonstration programs that allow Medicare funding for both curative and palliative care are being piloted in some states in the United States.[26] Such systems are already in place in the United Kingdom and other countries. Another limit is that Medicare coverage is geared toward home care, which presumes that patients have adequate housing and an at-home caregiver. Vulnerable patients who are homeless, who live in substandard housing, or who live alone are disadvantaged by this requirement. Many hospitals have developed palliative care services that are available as an adjunct to, or as an alternative to curative care, thus overcoming some of the barriers of hospice eligibility.

ADVANCED ILLNESS MANAGEMENT

For those patients in the United States who suffer from advanced illness who are receiving disease modifying or curative treatment, do not yet meet the US Medicare standards for hospice admission, or are not yet mentally or spiritually ready to accept hospice, there are emerging programs to provide a level of support that includes a multidisciplinary team approach with attention to comfort and quality of life. They also provide structures to aid in treatment adherence as well as communication between the patient and the medical team. As they are not bound by the same inclusion criteria as hospice or home care, these programs can often assist with more complicated regimens outside of the hospital, such as total parenteral nutrition or management of an outpatient patient-controlled analgesia device. These specifically trained teams also assist in care and in education and support of end-of-life decision making through the transition of decline toward hospice. Innovative programs such as Sutter Health System's award winning AIM[27] and the Hospice of Michigan's leading edge @HOMe Choices[28] programs are emerging throughout the United States. They have been shown to provide high-quality care, improve referrals to hospice, and lower costs for patients with advanced illnesses.[29]

OTHER COMMUNITY-BASED PROGRAMS

Vulnerability due to homelessness or social isolation can present multiple challenges to patients who might otherwise benefit from hospice or other palliative care services. Alternative systems are needed to address the special needs of these at-risk populations. An example is the partnership between a Mission Hospice and the Ottawa Inner City Health Project that brings cost-effective hospice and palliative care directly into homeless shelters. These services allow homeless persons who may be mistrustful of institutional living to receive needed care in more familiar environments.[30,31]

Potential social isolation of the elderly has been addressed in the Program of All-Inclusive Care of the Elderly (PACE) model of care that provides comprehensive services to disabled and nursing-home eligible elderly. Although not considered an end-of-life care provider, per se, these community-based programs have the benefit of providing continuity care and support to allow vulnerable elders to live outside of institutions. Their success may result from the "all-inclusiveness" provision: patients are enrolled for the duration of their life and all medical, social, rehabilitation, psychological, and other services must be obtained through the program. Clarifying patient preferences regarding end-of-life care begins at the time of intake and is regularly reviewed as part of the PACE treatment plan. As their enrollees face the end of life, coordinated comprehensive care is available to meet their needs.

CLINICAL ISSUES: PAIN AND SYMPTOM MANAGEMENT

Mr. Smith is discharged to his room in a boarding facility. Seeing his rapid decline over the ensuing weeks, a friend who resides in his boarding home calls an ambulance to transport him to the hospital. Upon arrival, the paramedics note that Mr. Smith is extremely weak and unable to stand. He is admitted to the hospital. The palliative care team reestablishes contact and does a thorough reevaluation, revealing that his pain has been poorly controlled for the past several days; they institute aggressive pain management.

HEALTH SYSTEM BIAS

The elderly, poor, and other vulnerable persons are at greater risk of their pain being misdiagnosed, inadequately assessed, or poorly managed compared to patients who are more privileged. In many countries, opiate medications are simply not available to the majority of patients suffering moderate or severe pain.[1] In the United States, formularies for less expensive health-care plans may make accessing some medications, transdermal preparations, for example, next to impossible. Physicians may fear regulatory scrutiny from federal and state agencies, or they may worry about drug diversion and thus may fail to prescribe opioids for patients with serious pain (see Chapter 38). These fears, along with the lack of physician training, however, do not account for the extent of inequities in pain treatment for minority patients in nursing homes, emergency rooms, cancer centers, and community pharmacies in the United States. Many studies have implicated provider and health system bias directed against racial and ethnic minorities as a potential root of these inequities.[32]

PHYSICIAN BARRIERS

Although many physician barriers exist to the implementation of a safe and effective pain regimen, patient and caregiver bias also can contribute to achieving adequate pain control. Some patients may refuse to take certain medications for pain due to their recognition of drugs of abuse within their community, or even because of a prior experience with a particular medication and a perceived poor outcome. For example, patients may refuse to take morphine because their spouse received morphine elixir minutes before their death and they carry a strong belief or fear that the morphine is what caused the end of their life. It is important to identify and address these issues. Furthermore, pain regimens should be kept as simple as possible and the role for each medication explained in a way the patient and caregivers can understand, as this will greatly increase adherence.

In addition to concerns with providing adequate pain relief, providers must attend to a range of other constitutional, organ system, and psychiatric symptoms that are part of the underlying disease or that arise during the active dying process. Dyspnea, the awareness of breathlessness, is a common distressing symptom at the end of life that may worsen as death progresses. Although it is a subjective sensation, like pain, it may result from underlying pulmonary, cardiovascular, or renal disease, or may be caused or exacerbated by anxiety. Other common symptoms at the end of life include nausea and vomiting, constipation or diarrhea, anorexia, and dysphagia. Anxiety, delirium, and agitation may also be present because of drugs, metabolic disturbances, infection, or brain lesions. When the causes of any of these symptoms are not apparent or easily determined, further identification of their underlying etiology may be difficult and in some cases unwarranted. For example, patients who are imminently dying should not be subjected to a battery of invasive tests whose results may take days to weeks to return. However, appropriate management of symptoms with the goal of improving the quality of life as well as quality of dying is an absolute, inviolable priority throughout the continuum of care.

- Social injustice contributes to early death and increased suffering in poor, underserved, and minority patients.
- Millions of people worldwide are in need of palliative care at the end of life.
- Dying in pain and without dignity is considered tantamount to torture.
- Health-care providers avoid discussing death or do so in language that is not understood.
- Cultural and social issues, critical to the lived experiences of vulnerable patients, are often ignored in end-of-life discussions.
- Trustworthiness of providers and institutions, an essential element to these discussions, may be a concern for underserved patients.
- Dying patients, particularly those from minority groups, are at greater risk for undertreatment of pain and other symptoms.
- Health-care providers wait too long before instituting palliative care measures and referring patients to hospice.
- Palliative care is not widely available to those with long-term, chronic illnesses but who are still pursuing curative care.
- Patients, families, and health-care providers are not fully aware of the range of palliative care services and options available to them.

APPROACHES TO THE CARE OF THE DYING PATIENT

> Once Mr. Smith's pain and other symptoms are adequately managed, the palliative care team discusses his limited prognosis with him. He continues to demonstrate capacity to understand his condition and to make informed decisions. He asked the doctor, "What would you do in my situation?" The doctor replies that Mr. Smith is clearly too weak to return to his prior living situation and recommends placement in a skilled nursing facility. She also recommends hospice care, and a referral is initiated. Resuscitation status is readdressed, and Mr. Smith agreed that, given his decline, a focus on comfort over aggressive interventions is his preference. A Do-Not-Attempt-to-Resuscitate order is written and a POLST is completed prior to his discharge to the nursing facility. He also asks the social worker to inform his friends at the boarding home where he was moving.

VALUES CLARIFICATION: PATIENT AND PROVIDER

Consumer groups have sought to empower patients to participate in decisions regarding their care. The Five Wishes (available through Aging with Dignity at http://www.agingwithdignity.org/) is one such program, developed to encourage patients to address their medical, personal, emotional, and spiritual values with their family and physicians. Recognized in most states to meet the legal requirement of an advance directive, the five wishes ascertain (1) the patient's proxy for health-care decisions; (2) what medical treatment, including life support, the patient wants; (3) desired comfort measures (regarding pain and symptom control); (4) desired care from other nonmedical personnel; and (5) disclosure parameters (i.e., what information can be disclosed and to whom).

Perhaps the first step in caring for the dying is for providers to recognize their own mortality and to explore how their life experiences influence interactions with patients. Indeed, personal self-awareness is a critical element in achieving cultural competence. Providers may ask personnel from local hospices or other palliative care organizations for support resources to identify and address their anxieties and fears. Providers with access to more than 320 health-care facilities around the United States that conduct Schwartz Center Rounds® may wish to avail themselves to their programs, which foster open and honest discussions on the social and emotional issues that arise in caring for patients.[33]

Clinicians would benefit from asking themselves the questions comprising the Five Wishes. In many family meetings, families will ask the provider, "What would you do?" Providers need to respond to this question with authenticity and appropriate self-disclosure. They should also become aware of the values they hold regarding the range of ethical issues that might arise in care for the dying. What is their own position regarding such issues as patient autonomy, truth-telling, and disclosure? They should consider how their stance might conflict with persons whose cultural values and preferences differ from their own. For example, it is important that a clinician acknowledge his or her own feelings before facing an immigrant patient's family who insists that the patient be shielded from a terminal diagnosis.

SOCIOCULTURAL COMPETENCE

Many hospice and palliative care organizations have felt the impact of changing demographic characteristics (increasing numbers of older, multicultural, and multiethnic populations) and have responded with efforts to increase the cultural competence of the palliative care workforce.[34]

Providers should become aware of the unique cultural, economic, sociopolitical, and historical backgrounds of the populations they serve. This will contribute to a better understanding of clinical issues, and may provide an opportunity for patients to tell their own story and to feel cared about. It may also enhance the perception of provider trustworthiness, an essential element in the provider–patient relationship. In turn, it is incumbent on the provider to examine negative attitudes they may hold toward certain populations and to strive to eliminate behavior that may be discriminatory.

Strategies for culturally appropriate communication are appropriate in the care of vulnerable patients, as well. In general, when language barriers arise, the use of trained medical interpreters is crucial (see Chapter 31). Even when patients and providers share the same language, it is important that the provider make explicit inquiries to check if understanding is present. Often, asking patients to offer their explanatory model of their illness can reveal gaps in health literacy that can then be addressed.

CLINICAL COMPETENCE

Until recently, the skills needed to manage pain and other distressing symptoms, coordinate care in interdisciplinary teams, communicate effectively with patients and families, and assess grief and loss were not part of standard US medical education. Fortunately, this is changing, as demonstrated by new mandates in many states for continuing education in pain and palliative care as a requirement for physician license renewal.

Several educational programs have been developed to improve the full range of end-of-life care skills and competencies. The American Medical Association's Education for Physicians on End-of-Life Care (EPEC) (http://epec.net/) program, available online, combines multimedia

presentations, exercises, and discussions emphasizing communication, ethical decision making, palliative care, psychosocial concerns, and symptom management. Training sessions are available in most major US cities or online. EPEC has been adapted for use in specific populations such as African American or for the elderly[35,36] (http://epec.net/adaptations.php). Other educational programs targeting clinicians are also available, such as the American Academy of Hospice and Palliative Medicine self-study UNIPAC (http://aahpm.org/self-study/unipacs) curriculum.

Programs such as EPEC have also been adapted for other health-care providers. An equivalent educational resource for nurses with international outreach is available through the End-of-Life Nursing Education Consortium (ELNEC)[37] (http://www.aacn.nche.edu/ELNEC/). The Institute for Palliative Care at California State University in San Marcos has developed a series of training courses for nurses, social workers, and chaplains.[38] A Web-based comprehensive database of peer-reviewed educational materials is available through the Center to Advance Palliative Care (https://www.capc.org/fast-facts/). This includes Fast Facts files: continuously updated, peer reviewed, one-page outlines of key information on important end-of-life clinical topics for end-of-life educators and clinicians.[39]

CONCLUSION

> Mr. Smith died in the nursing home 2 weeks later, surrounded by a hospice chaplain and nurse and a friend from his boarding home.

Among the disenfranchised who are at risk for dying anonymously and alone, the need for companionship at the time of death is an important consideration. Personalized programs on palliative and end-of-life care for vulnerable population groups are becoming more readily available to maintain patient dignity and provide compassionate care for the dying vulnerable.[40]

With the advent of the hospice movement over 30 years ago, and more recently, through grassroots, philanthropic, and special interest advocacy, care of the dying has undergone transformation in most developed countries. Globally, there is increasing recognition of palliative care needs as a public health issue.[41-43] Yet, to date, only 8% of countries have integrated palliative care into their health-care system.[1,44] In the United States, practice guidelines and continuing educational programs are available to improve clinician end-of-life care skills and competencies. The unique concerns of the vulnerable dying can be addressed by advocating for reforms in health-care delivery and for financing that eliminates the barriers to quality care.

Strategies for End-of-Life Care for Vulnerable Persons

Identified Problems	Strategies
Values clarification	• Become aware of personal anxieties and fears regarding death; refer to palliative care teams if necessary and available or seek support from local hospice or other organizations that care for the dying. • Complete a living will, Five Wishes, or other advance directive to be aware of concerns patients raise when asked to do the same.
Conflicting values	• Identify personal values regarding ethical principles. • Elicit patient's expectations for care. • Identify shared values. • Be willing to modify own position to reach a mutually acceptable approach. • Seek consultation or assistance from other health-care workers, institutional ethics committee, or community or religious leaders when necessary.
Communication: general concerns	• Be alert for problems, even when patient and physician share the same language or use local dialects. • Check explicitly that patient and physician have understood each other.
Language barriers Links to low literacy and other languages	• Use trained medical interpreters. • When possible, avoid using family or friends of patient to translate.
Caring for specific populations: inequities and social justice	• Increase knowledge of the cultural, economic, sociopolitical, and historical contexts through guidebooks, community representatives, religious leaders, or professional colleagues. • Honestly examine negative attitudes held toward certain populations and strive to eliminate behavior that may be discriminatory.

	• Respectfully inquire about past or present incidents that may have engendered mistrust. • Listen to the patient's story and acknowledge his or her experience. • Address issues that the patient identifies as important.
Clinical issues	• Follow clinical practice guidelines developed to improve quality care. • Maintain continuing education in pain and palliative care. • Encourage interdisciplinary engagement to provide comprehensive care across medical, social, cultural, and spiritual domains.

Delivering Bad News

Steps	Rationale
1. Setting up: Prepare beforehand	Attending to the environment in advance enhances the comfort of all parties and ensures privacy. Determine in advance who should be present, making sure to include significant members of the patient's family or social network. Make sure all members from the health-care team who are present are informed of the goals of the conversation.
2. Find out how much the patient and their family already knows.	Questions such as "What have you been told about your condition?" and "What is your understanding of what is happening medically for you?" can identify any misunderstandings and assess the patient or family's comprehension of medical concepts.
3. Find out how much the patient wants to know.	Asking "What information would be most helpful to you at this point?" allows you to tailor the conversation to their specific information needs.
4. Deliver the information in a straightforward manner, allowing adequate time for discussion.	Avoiding medical jargon, share the information requested compassionately and directly (e.g., "I'm sorry to say that your test results show that the cancer has spread").
5. Once the news is delivered, give the patient time to take it in, and allow for emotional reactions.	Do not rush to fill the silence. Allow for sadness, grief, or shock. Offer empathic responses (e.g., "I'm sorry that this isn't the news we wanted to hear.")
6. Lastly, make plans for follow-up	Strategize a plan for future follow-up. This includes identifying any emotional support needed after the meeting as well as summarizing next steps.

Working in Interdisciplinary Teams to Provide Care for the Dying

Steps	Rationale
1. Identify staff across medical, social, emotional, and spiritual disciplines that are relevant to patient needs and care goals.	Independent or autonomous management of a case may limit the overall efficiency of care delivery.
2. Gather these staff members for the purpose of sharing assessments of the patient and/or family needs and to identify an overall plan of care.	Clinical practice guidelines for palliative care assert that comprehensive and timely interdisciplinary assessment of the patient and family should form the basis of the plan of care.
3. Minimize hierarchical or power differentials in the team.	Allowing each person to identify their area of expertise can enhance appreciation by others of their unique and important contributions to the team. Creating an atmosphere where all persons feel comfortable to talk and share ideas can foster team building. One example is to rotate leadership roles (e.g., leading discussions) to keep all members involved and engaged.
4. Coordinate specific responsibilities for each team member.	Disciplinary responsibilities may sometimes overlap. Coordinating responsibilities ensures that care plans are followed through.
5. Encourage ongoing discussion and collaboration	Regularly scheduled team meetings ensure effective and timely communication about patient needs and care plans.

DISCUSSION QUESTIONS

1. An elderly homeless man has a recent diagnosis of adenocarcinoma of the lung. Given the grim prognosis of this disease, what structures and processes of care are needed to ensure the patient's quality of life?
2. What ethical principles should be considered in contemplating the Do Not Resuscitate (DNR) status for

a patient in a persistent vegetative state if no prior advance directive is available? How might you assess the patient's values and preferences if he or she is unable to express them? In such cases, which principle, substituted judgment versus best interest, would trump the other in making that decision?

3. How can barriers to hospice referrals and utilization be overcome to make this service more widely available? What alternative delivery models for quality palliative care are available?
4. How can providers and their professional organizations advocate for changes in the health-care system that meet the needs of dying patients?

RESOURCES

Aging with Dignity Five Wishes Program: http://www.agingwithdignity.org/5wishes.html.

American Academy of Hospice and Palliative Medicine: http://www.aahpm.org/.

Center for the Advancement of Palliative Care: http://www.capc.org.

End of Life Nursing Education Consortium (ELNEC): http://www.aacn.nche.edu/ELNEC/.

EPEC(c): The Education in Palliative and End-of-Life Care Curriculum: http://www.epec.net/.

Frontline: Being Mortal: http://www.pbs.org/wgbh/pages/frontline/being-mortal/.

National Consensus Project: http://www.nationalconsensusproject.org.

National Hospice and Palliative Care Organization: http://www.nhpco.org/.

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Chapter 25

Work, Living Environment, and Health

Michael Guarnieri, MD, Janet Victoria Diaz, MD, and John R. Balmes, MD

Objectives

- Summarize occupational and environmental risks.
- Review epidemiology of occupational and environmental exposures and illness.
- Describe occupational and environmental risk assessment.
- Review preventive and therapeutic interventions to decrease environmental and occupational illness.
- Review the effect of urban and community planning on health.

Arnulfo Perez, an undocumented day laborer, receives a laceration falling off a ladder. He works 14 hours a day, primarily in construction or painting projects. He does not have a steady employer, has never received any job safety training, and has never heard about worker's compensation or unions. He shares a single room apartment with six friends. He is paid in cash. He knows that without a bank account to store his earnings, and fearful of reporting thefts to the police, he is vulnerable to being assaulted.

INTRODUCTION

The environmental and occupational safety of residential and work places have an enormous impact on people's health. Public health measures implemented during the 20th century have improved people's living and working environments, resulting in increased longevity. However, dangerous occupations and harmful environmental exposures continue to be major contributors to disparities in health.[1-3] Health-care providers also often ignore these important risk factors for disease.[4,5] In addition, it is important to consider how individual susceptibility and social vulnerability may influence the health risks related to specific hazards (see Box 25-1).[6]

This chapter reviews adverse health issues attributable to environmental hazards in the workplace and at home, highlighting their disproportionate effect on vulnerable populations and presents practical approaches for preventive and therapeutic interventions to improve screening and care of patients with work and environmentally related illnesses.

ENVIRONMENTAL AND OCCUPATIONAL CONTRIBUTIONS TO INJURY, ILLNESS, AND DEATH

UNEMPLOYMENT AND HEALTH

Unemployment is an important risk factor for the ill health faced by poor and minority populations. Unemployed workers have higher rates of morbidity and mortality caused by multiple diseases, most prominently cardiovascular disease and suicide.[7-10] It has been hypothesized that

Box 25-1. Susceptibility to Environmental and Occupational Hazards

Occupational/ Environmental Hazard	Individual Susceptibility	Social Vulnerability
Inadequate housing • Heat/cold exposure • Chemical: lead, tobacco, indoor air pollution • Biological: pests and mold Neighborhood hazards • Lack of green space • Food availability • Neighborhood violence • Pollution: urban air pollution, proximity to sources Workplace hazards • Chemical exposures • Accidental injury • Heat stress	• Age • Gender • Comorbid disease • Genetic factors • Individual stress • Unemployment • Economic hardship • Job training • Use of personal protective equipment	• Race and ethnicity • Social isolation • Socioeconomic status • Immigration status • Political disenfranchisement • Job security • Educational status • Health status • Housing insecurity • Legal status • History of incarceration

recessionary economic cycles, characterized by unemployment and decreased income, may have profound negative effects on population health, especially for those on the lower rungs of the socioeconomic ladder.[11] While some of the indirect effects of recession may improve the health of the population (e.g., people cut back on driving and there are fewer accidents), people who are directly affected by loss of their homes or jobs have deteriorating health. Men who lose their jobs have higher mortality for a decade[12] and are more likely to develop a new health condition than their employed counterparts. Undergoing foreclosure is also often accompanied by declines in health.[13] Unskilled and semiskilled workers in cyclic industries are among the earliest to become unemployed, and remain so for the longest periods. Economic downturns have a negative impact on mental health. Increased morbidity and mortality may result from the stress of unemployment, compounded by a lack of access to healthcare. Workers who enter long-term unemployment following a structural change in the economy (e.g., after the introduction of a new technology such as automated harvesting machinery) often have inadequate education or native language proficiency to obtain new jobs in different sectors when the economy recovers. Low-wage, migrant, minority, recent immigrant, female, and older workers are particularly vulnerable.

RACE-BASED DISCRIMINATION IN THE WORKPLACE

Race-based discrimination at work can lead to increased stress and poor health.[14,15] Several studies suggest that stress from racial discrimination may be associated with mental health disorders, hypertension, coronary artery disease, and poorer pregnancy outcomes.[15] In a cross-sectional observational study of 356 African Americans from Atlanta, the likelihood of a physician diagnosis of hypertension increased significantly in patients who perceived high levels of stress from race-based discrimination.[14]

HOUSING AND THE BUILT ENVIRONMENT

As a majority of our time is spent indoors, mostly at home, inadequate housing quality has important health implications, exposing occupants to the following hazardous conditions: poor insulation, indoor air pollution (smoke from biomass stoves; nitrogen and sulfur dioxides from gas appliances), inadequate water and sanitation, cockroach and rodent infestation, dust mites, hypothermia and hyperthermia, dampness, mold, dangerous levels of lead in contaminated dust, residential soil, fire hazards, deteriorating structural integrity, and lead-based paint.[16,17]

The majority of global urban growth is occurring in low- and middle-income countries (LMIC), with up to 40% of growth occurring in urban slum housing.[18] In the United States alone, 10.7 million families live in substandard housing (i.e., deteriorating houses or apartments) and Latino and African-American families are disproportionately represented. These housing hazards have been associated with a variety of adverse health outcomes.[19,20] A cross-sectional analysis found that neighborhoods with a high "broken windows" index (i.e., the sum of percentages of homes with major structural damage or boarded-up vacant housing units; the percentage of streets with garbage, abandoned cars, or graffiti; and number of building code violations in public high schools) also had higher rates of premature death from all causes and from several specific causes (e.g., diabetes, homicide, suicide) and higher rates of sexually transmitted diseases.[21,22]

Overcrowding and poor-quality housing also have been associated with poor mental health, developmental delay, heart disease, and even short stature.[16] Unfortunately, the most vulnerable populations (infants, children, elderly, and chronically ill) are those who spend the most time indoors and are often socially isolated, making them less able to avoid these hazards.

Despite declines in the prevalence of lead poisoning in the United States, children aged 18–36 months living in

poor and inner-city communities continue to be at high risk for lead poisoning. Additionally, lead continues to be used in many other parts of the world in paint, gasoline, ceramics and pottery, cans, and countless other products.[23] Lead poisoning can result in neurologic damage, reduced IQ, hyperactivity, increased aggression, and learning disabilities.

Exposure to excessive heat during summer heat waves is another housing-quality problem that primarily affects elderly persons living in older homes with inadequate ventilation and cooling. The health effects from extreme heat events are likely to become more frequent due to climate change.[24] Distributing electric fans, providing air conditioning in specific areas of apartment buildings, and transporting the elderly to air-conditioned areas can reduce heat-related mortality.[25] Community action plans that involve public service workers to keep an eye on socially isolated elderly individuals during heat waves have proved effective.[26] More information can be found in the World Health Organization's Heat-Health Action Plan (http://www.euro.who.int/en/health-topics/environment-and-health/Climate-change/publications).

The CDC defines the built environment as "all of the physical parts of where we live and work (e.g., homes, buildings, streets, open spaces, and infrastructure)."[27] Characteristics of the built environment, such as low walk/bike-ability, lack of safe access to green space and recreation areas, and low neighborhood availability of healthy food options, promote poor nutrition and a sedentary lifestyle that increase the risk of obesity.

Lack of access to safe drinking water and improved sanitation, either in homes or publicly accessible locations, also remains a widespread problem in LMICs resulting in tremendous morbidity and mortality from infectious disease transmission and chemical contamination (e.g., arsenic, nitrates, and perchlorates) of drinking water.

NEIGHBORHOODS AND VIOLENCE

A neglected and disorderly physical environment increases the risk of crime. Homicide is the fourth leading cause of preventable deaths in the United States. Latino and African-American men aged 18–50 years are disproportionately represented in these deaths.[28] Economic deprivation, social disorganization, and acculturation are independent risk factors for homicide mortality among Mexicans and African Americans. Residents of public housing surrounded by green space had a stronger sense of community and reported using less violent ways of dealing with domestic conflicts.[29] Community and/or hospital-based violence prevention programs can reduce the risk of violence perpetration, violent victimization, and promote nonviolent self-efficacy.[30-32]

AIR POLLUTION AND HEALTH

While many higher income countries have witnessed improvements in ambient air quality in the wake of effective clean air regulation, the benefits remain unevenly distributed. More than 80% of the residents of poor urban centers in the United States are ethnic and racial minorities. These populations are chronically subjected to poor air quality because they live in close proximity to transportation facilities (bus depots, trucking stations, rail yards, and ports), high-volume roadways, waste treatment stations, power plants, toxic waste sites, refineries, and industrial facilities. Additionally, industrialization and urbanization in some LMICs have resulted in dramatic deterioration in air quality, particularly in the mega-cities of East and Southeast Asia.

Common urban air pollutants include nitrogen dioxide (NO_2), ozone, carbon monoxide, particulate matter, sulfur dioxide, and lead (the United States Environmental Protection Agency [EPA] regulated criteria pollutants[33]), as well as toxic air contaminants.[34] These are strongly associated with excess cardiopulmonary mortality, increased healthcare use, asthma exacerbations and possibly incident asthma, decreased lung function, increased respiratory symptoms, increased airway reactivity, and lung inflammation.[34,35] Other pollutants, the so-called toxic air contaminants (e.g., benzene or perchloroethylene) are known to be associated with cancer and reproductive abnormalities.[34]

Because lung growth continues into early adulthood, children are especially vulnerable to respiratory tract toxicity from urban air pollution. A longitudinal study of children from southern California reported that exposure to high levels of air pollutants was associated with decreased growth of lung function over an 8-year period and clinically significant decreased forced expiratory volume in 1 second (FEV_1) by the age of 18 years.[36] A number of studies have also shown adverse effects of urban air pollution on birth outcomes. For example, a prospective study of minority pregnant women in New York City reported that exposure to high levels of urban air pollutants (specifically, polycyclic aromatic hydrocarbons) was associated with decreased birth weight and head circumference among African-American newborns.[37] Finally, asthma morbidity and mortality rates are highest among African Americans, especially children, living in urban areas and are associated with high levels of ambient pollution.[38]

In LMICs, approximately 3 billion people continue to use solid fuels for cooking or heating (including coal, wood, crop residues, and dung).[39] Smoke exposure from solid fuel use has been associated with cardiovascular disease (Box 25-2), chronic obstructive pulmonary disease (COPD), lower respiratory infections, lung cancer, and cataracts; this may be an important risk factor to consider in immigrants from countries that continue to rely on these fuels.[40]

Box 25-2. High-Risk Occupations for Heart Disease

Men		Women
Air traffic controllers	Paper industry workers	Bus drivers, taxi drivers
Bakers	Police, Protective service workers	Cleaners
Bus drivers, taxi drivers, truck drivers	Prison wardens	Waitresses
Butchers	Rubber and plastics workers	Rubber and plastics workers
Cannery workers	Sea pilots	Paper workers
Cooks, waiters	Warehousemen, storekeepers	Self-employed in hotel and catering
Fire fighters	Home help	
Fishermen, ship's deck officers	Unskilled in tube, sheet, and steel construction	
Foundry workers	Hairdressers	

From Tüchsen F, Landsbergis P. High-risk occupations. Forum on the Way We Work and Its Impact on Our Health. Los Angeles, April 22–23, 2004.

FATALITIES IN THE WORKPLACE

Ethnic and racial minorities are disproportionately represented in occupations with higher risks for fatal injuries.[41-44] Foreign-born workers account for 42% of the growth of the US labor force and their workplace fatality rate is on the rise, whereas the national workplace fatality rate has declined.[43] Latinos and younger workers suffer the highest rates of workplace fatalities and the majority worked in the following five occupations: (1) transportation and material moving; (2) handlers, equipment cleaners, helpers, and laborers; (3) farming, forestry, and fishing; (4) construction trades; and (5) security. In all five industries, foreign-born workers experienced higher fatality rates than their native-born coworkers.[45] The most common fatal events were highway motor vehicle incidents (22%), violence (17% including homicide and suicide), and falls to a lower level (13%).[46] Reasons for increased mortality of foreign-born workers include higher rate of employment in hazardous jobs, longer hours, piece-work incentives, and less training.

In the United States, workplaces associated with the highest rates of homicides are taxicab establishments, liquor stores, gas stations, detective or protective services, justice or public safety facilities, and grocery and jewelry stores.[47] Other risk factors associated with homicides include male gender, working early or late hours, working in high-crime neighborhoods, and occupations engaged in the exchange of money or valuables. Finally, elderly workers and adolescents suffer from workplace homicides at a higher rate than others.[48] Elderly workers likely are less able to defend themselves when assaulted and are at increased risk of dying from an assault. Younger workers who are foreign born have higher rates of being killed at work.

NONFATAL OCCUPATIONAL INJURIES

Laborers or unskilled construction workers are more likely to suffer from serious injuries requiring hospitalizations than are more-skilled workers.[41] Urban dwelling workers, both men and women, who are injured on the job tend to be young and unskilled. Their injuries commonly affect the musculoskeletal system and have an impact on their immediate ability to work and their long-term health.[42]

SELECTED OCCUPATIONS AND EXPOSURES AND THEIR IMPACT ON HEALTH

MIGRANT FARM WORK AND HEALTH

The agricultural industry is another inherently dangerous industry. It employs less than 2% of the US workforce but is responsible for 10% of workplace fatalities.[49] The agricultural industry employs approximately 4 million migrant and seasonal farm workers. A migrant farm worker establishes a temporary home in order to do seasonal agricultural work, while a seasonal worker does not migrate.[50] Migrant workers and their families are among the most underserved and understudied populations in the United States. Nearly all migrant and seasonal farm workers are ethnic and racial minorities; 90% are Latino and the remainder African American or non-Latino Caribbean.[50]

Migrant workers are at risk for various work-related illnesses, including pesticide-related illnesses, musculoskeletal strains/sprains, traumatic injuries, noninfectious respiratory diseases, dermatitis, infectious disease, cancer, eye problems, and mental health problems.[47] The burden of these problems is exacerbated by minimal access to health care. The children of migrant farm workers may also be expected to work in the fields after school, be exposed to harsh working conditions, and have an increased rate of dropping out of high school.

SUBSTANDARD HOUSING FOR MIGRANTS

The migratory nature of farm workers places them at risk for social isolation and living in substandard housing. Social isolation is a result of separating nuclear families

and has been associated with stress, anxiety, depression, and substance abuse.[47] Substandard housing creates crowded and unsanitary conditions and has been associated with higher rates of communicable diarrheal illnesses and tuberculosis.

PESTICIDES AND HEALTH

The Environmental Protection Agency estimates that 10,000–20,000 physician-diagnosed pesticide poisonings occur each year among the approximately 2 million US agricultural workers.[48] Exposure results from absorption through the skin, direct spraying, or accidental ingestion. Although exposure to organophosphate pesticides can result in acute toxicity characterized by headache, rash, nausea, vomiting, disorientation, shock, respiratory failure, or, in most severe cases, death, most exposures to pesticides are low-moderate levels and present with dermatitis, eye irritation, or more diffuse complaints. Children are at particular risk for both acute pesticide poisoning and neurodevelopmental effects from less acute exposures.[51]

Although good data on the chronic health effects of low-moderate levels of pesticide exposure among migrant and seasonal farm workers are limited, some studies suggest that farm workers are at higher risk for cancer and neurological and reproductive abnormalities. In all scenarios, the pesticide or its residues can be deposited on the farm workers' clothing and then be brought home to expose family members, which may include pregnant women and young children, who may be particularly vulnerable to toxic effects.[37] Schools in agricultural areas may be in close proximity to fields where pesticides are applied, potentially exposing young children.

To protect farm workers from pesticide exposure, the EPA implemented Worker Protection Standards (WPS) and the Occupational Safety and Health Administration (OSHA) developed regulations.[52] The WPS states that employers must centrally post information about pesticide application (name, location, date of application, re-entry period), place warning signs around fields just sprayed with a re-entry date, and provide safety training to farm workers.[49] The OSHA regulations mandate that adequate sanitation facilities be available in the field, including potable drinking water with individual cups, toilets, and hand washing facilities.[53] Similarly, farm worker housing must have adequate showering and laundry facilities.

In a study of Latino farm workers from North Carolina, a high percentage experienced both wage violations, especially if they were illegal immigrants, and pesticide safety violations.[50] Similarly, many farm workers lack field toilets, laundry facilities, or any pesticide training.[51] Despite federal and state regulations to promote the health of migrant and seasonal farm workers, they remain at high risk for pesticide exposure and poor health, and are likely less able to access appropriate help for themselves and their families. In LMICs where there is less regulatory control, exposures to pesticides can be quite high among self-employed farmers and their families.[52] The World Health Organization has a program, the WHO Pesticide Evaluation Scheme: "WHOPES," to provide norms and standards to protect public health in all countries.

Recognition of pesticide exposures is a challenge for prevention, treatment, and reporting, even if they are common. The EPA and the National Environmental Education and Training Foundation (NEETF), in collaboration with the US Departments of Health and Human Services, Agriculture, and Labor, have created an initiative, the National Strategies for Health Care Providers: Pesticide Initiative, to improve the ability of health-care providers to recognize pesticide exposures and manage pesticide-related health problems (see "Resources" section).

Pesticides are not the only toxins that might cause harm to agricultural workers. Plant toxins themselves (e.g., nicotine from handling tobacco leaves), animal confinement building environments, grain dusts, diesel exhaust, and solvents are examples of other types of exposures that may have serious impacts on health.[53]

APPAREL INDUSTRY AND HEALTH

Minority immigrants often find work at facilities manufacturing goods in highly competitive sectors where there is a premium on low labor costs, for example, the apparel industry, known as sweatshops. These jobs involve repetitive motion, and often are associated with a high risk of exposure to potentially harmful chemicals. Several investigations of garment workers both in the United States and those in maquiladoras along the Mexican side of the United States–Mexican border have documented increased risk of musculoskeletal disorders and acute health effects consistent with excessive exposure to chemicals, such as solvents.[54,55] In LMICs like Bangladesh, not only are sweatshop working conditions prevalent but also the buildings themselves may be unsafe. Additionally, there are an estimated 168 million child laborers worldwide, with many of these working in hazardous conditions in the apparel industry.[54]

HOSPITALITY INDUSTRY AND HEALTH

Room cleaning jobs in the hospitality industry are characterized by increasing repetitive physical workloads, low income, low skill use, low job control, and virtually no prospects for training and career advancement. These workers are largely female, immigrants who speak a native language other than English, and older than

50 years. The hospitality industry has experienced a wave of restructuring, consolidation, and new practices to cut costs, including lean staffing and greater performance demands on the workforce. A recent study found an association between poor working conditions and reduced health in hotel room cleaners. Room cleaners reported increasing physical workloads in recent years, and a large proportion of room cleaners were exposed to high levels of job stress. The study also found that room cleaners have high rates of work-related pain and disability, and that self-reported general health of room cleaners is below the national average.[55] In addition, the hospitality industry has become a major target for welfare-to-work and job training programs in cities throughout the country.[55]

Janitors in other work environments are at risk of job-related illness. Many are immigrants who speak a native language other than English (especially Latinos), have limited literacy in their native language, work multiple jobs, and usually do not have personal transportation. They tend to be unfamiliar with workplace rights, receive limited, if any, training, and infrequently use protective equipment. Often employers use intimidation to silence workers about work place hazards, illness, or injury. Many suffer deteriorating physical health, skin rashes, asthma, headaches, back injuries, repetitive motion injuries, pregnancy complications, and mental and emotional stress. A European study has documented that cleaning is associated with increased risk of occupational asthma.[56]

OCCUPATIONAL ASTHMA

Occupational asthma is the most common occupational lung disease. It is estimated that 15% of all adult-onset asthma is caused by occupational asthma and many more have their asthma aggravated by workplace exposure. Prognosis is directly related to the duration of time between onset of symptoms and removal of the cause. The earlier it is recognized and treated, the better the prognosis for the patients. Health-care workers should ask all adult asthmatic patients about their work. Occupational asthma should be suspected in any newly diagnosed adult asthmatic; any patient with cough or wheeze that improves on weekends or holidays; any patient working in a high-risk occupation, especially if they have other symptoms of atopy such as allergic rhinitis or eczema; and in an otherwise unexplained exacerbation of previously well-controlled asthma.

There are more than 300 agents suspected of causing occupational asthma. At-risk occupations include spray painters, agricultural workers, bakers, health workers (allergy to latex gloves), animal handlers, and hairdressers. The key to treatment is removal from exposure. Studies have shown a direct link between length of time of exposure and persisting asthma. Reduction and removal of exposure is also important for those asthmatics whose asthma is exacerbated by workplace exposure.

UNINTENTIONAL INJURY IN CHILDREN

Unintentional injuries are the leading cause of death among children ages 1–19 years, almost 40% of all deaths in this age group. Poverty, crowding, single-parent households, and low maternal age or educational achievement make children more likely to be injured. About 25 children in the United States die a day from injuries. Common causes of fatal and nonfatal unintentional childhood injuries include drowning, falls, fires or burns, poisoning, suffocation, and transportation-related injuries. Poisoning deaths have tripled in the last three decades and are now the most frequent cause of death from injury in the United States; 9 out of 10 poisoning deaths are caused by drugs and a majority of these deaths are due to prescription opiates.[57] To tackle the problem in the United States, the Centers for Disease Control and Prevention (CDC) created the National Action Plan for Child Injury Prevention to complement the World Health Organization/UNICEF's programs to prevent injury internationally.[58]

- Those from poor and minority groups are at high risk for fatal and nonfatal work injuries and violence.
- Construction, migrant farm work, taxi cab driving, and retail sales work in small, all-night stores are dangerous occupations.
- Morbidity and mortality resulting from respiratory and cardiovascular disease are strongly associated with poor housing and urban air pollution.
- Health-care providers often do not assess occupational and environmental risk.
- Interventions (such as hazard recognition training and personal protective equipment), although useful, are suggested infrequently by health-care professionals.

PREVENTIVE INTERVENTIONS

> Environmental justice is the belief that all people and communities have the right to live, work, and play in places and communities that are safe, healthy, and free of life-threatening conditions.[14]

Each clinical encounter with a patient provides an opportunity to assess environmental and occupational health risks. Clinicians have a vital role to play by recognizing, treating, and preventing problems. Communication among health-care providers, public health agencies, researchers, employers, community organizers, and urban planners

completes the process necessary to promote health equity and environmental justice.[17,59]

SCREENING

Failure to take an exposure history is one reason that environmental and occupational illnesses often go unrecognized. Many of these illnesses are associated with nonspecific medical complaints and without a basic exposure history may never be linked to their actual cause. All patients, but particularly poor and minority patients, should be questioned about their occupations and living environments, including job description, safety training, neighborhood, and housing. Screening for possible occupational or environmental exposures with a few simple questions is the most practical first step (Box 25-3).

OCCUPATIONAL AND ENVIRONMENTAL HISTORY

If the clinical presentation or initial medical history suggests a potential occupational or environmental exposure, a detailed exposure interview is needed. A complete job description should include specific work tasks, work hours, product(s) manufactured or service(s) provided by the employer, any exposures to dust or fumes, workplace discrimination, and stress. Linking timing of symptoms with exposures is also important. The Agency for Toxic Substances and Disease Registry (ATSDR) publishes a handy guide to taking a detailed exposure history including a useful form (see "Resources" section).

Adequate safety training is an important intervention that can reduce risk of occupational injury or illness. If a worker has not received training (e.g., about the risks of lead intoxication from removing old house paint), then referral to an occupational medicine specialist, nurse, industrial hygienist, or safety specialist is in order. The information that needs to be provided includes the inherent risks of the job, interventions that may decrease these risks (e.g., the use of personal protective equipment such as gloves or respirators), and instruction about where to receive timely medical care and the right to workers' compensation if injured on the job. Special attention should be given to those in the most dangerous occupations to ensure that they are receiving appropriate workplace safety training. Most local health departments have occupational and environmental health units that can provide such training.

Losing a job can have profound health consequences for a low-wage, minority worker. It is often better to try to keep such a patient working at a job that has potentially harmful occupational exposures with appropriate efforts to reduce the exposures than to advise quitting the job. It is always possible to ask for an OSHA inspection of what appears to be an unsafe workplace, but the affected worker should always be asked for his/her permission because such a request can have employment repercussions.

Box 25-3. Screening Questions for Occupational and Environmental Exposures

Adults

- What kind of work do you do?
- Do you think your health problems are related to work, home, neighborhood, or other location or activity?
- Are your symptoms better or worse when you are at home or at work? Do your symptoms improve on long weekends or vacations from work?
- What hobbies do you have?
- Are you now or have you previously been exposed to pesticides, solvents, or other chemicals, dusts, fumes, radiation, or loud noise?
- Have you received safety training/personal protective equipment (for eye, ear, respiratory, and skin protection) and do you follow it?
- Do you live near a major road or industrial facility?
- Does your home have water damage?

Agricultural workers

- Are pesticides being used at home or work?
- Were the fields wet when you were picking?
- Was any spraying going on while you were working in the fields?
- Do you get sick during or after working in the fields?
- Have you had problems with rashes or eye irritation after working?
- Do you have the opportunity to bathe and change clothes after work?
- Are you notified when spraying is occurring and have you received safety training/equipment?

Children

- Do you think the child's health problems are related to the home, neighborhood, day care, school, or other location or activity?
- Has there been any exposure to pesticides, solvents or other chemicals, dusts, fumes, radiation, or loud noise?
- What kind of work do the parents or other household members engage in?
- How are cleansers, pesticides, medications, and firearms stored at home?
- Was your house built before 1978? Is the paint in poor condition?

NEIGHBORHOOD AND HOUSING

Questioning about housing quality, neighborhood safety, and air pollution is also important. An adequate housing conditions history should ask about the presence of poor

insulation, combustion appliances, cockroach and rodent infestation, carpets, heating availability, stove type and fuel use, moldy walls, lead paint, and unaffordable rent. If a house was built before 1978, it might well have lead paint. Peeling paint is particularly problematic. If children are playing in areas of bare soil, concerns over lead levels are warranted. Neighborhood safety should be assessed from the patients' perception of safety and green space availability. If violence prevention programs are available, participation of victims in such programs should be encouraged.

AIR QUALITY

A complete air pollution exposure history may be difficult to elicit from the patient because many are unaware of local polluting facilities. Patients should be asked about their physical proximity to transportation facilities (bus depots, trucking stations, rail yards, and ports), high-volume roadways, waste treatment stations, power plants, refineries, and polluting industrial facilities. Given the known effects of urban air pollution on health, it is a physician's responsibility to have general knowledge of the community's pollution sources. This information should be obtained from environmental agency Web sites, distributed among the health-care providers working in the community, and then shared with patients. Patients with preexisting heart and lung conditions should be advised to pay attention to air quality advisories in the media.

Special attention should be given to patients who are elderly and those with asthma, COPD, and cardiovascular disease or with young children to ensure that any housing and environmental hazards are detected. To do so, an environmental health specialist, usually from the local health department, can perform a home assessment.

PREVENTIVE ADVICE

If no clear risk is identified, health-care providers should provide general preventive advice to maintain occupational and home safety. For example, firearms, cleaning products, and garden products should be stored safely and away from children's reach, and product labels should be read to assure proper use. Patients should be counseled on the risks of drug overdose if medications are not used as prescribed and to store medications in their original packaging, out of children's reach, and in a locked medication cabinet when possible. Pregnant and breastfeeding women in particular should be advised to use chemicals cautiously.

The US CDC recommends the following measures to minimize risk for potential lead toxicity: minimize children's access to peeling paint, regular washing of children's hands and toys, regular cleaning of surfaces in at-risk homes, prevent children from playing in bare soil, and avoid renovations in housing built before 1978 where children and pregnant women are living. Home lead testing may be available through state or local health departments for those living in at-risk homes. Carbon monoxide monitors should be installed in homes with indoor gas heaters. Counseling parents on age-appropriate use of motor vehicle restraints in children has been associated with short-term increases in use.[60] However, the long-term impact of such counseling and incremental benefit over vehicle restraint legislation is less clear. Counseling on the use of bicycle helmets appears to encourage their use, and bicycle helmet interventions may be even more effective in younger children (younger than 12 years).[61]

THERAPEUTIC INTERVENTIONS

Once an occupational or environmental illness or injury is suspected, the clinician has two concerns: the care of the individual and the health of the community. Referral to an occupational health specialist may assist in both areas.

GENERAL GUIDELINES

If one suspects that a patient's illness or injury is related to a chemical or physical exposure, it is important to consider whether the signs, symptoms, and timing make sense for the suspected exposure. For example, a patient's exposure to asbestos from a building renovation project, even if heavy for days or weeks, should not produce any acute symptoms.

Identification of the specific agent(s) responsible for causing a health problem is often critical to effective management. If there is a concern about a chemical exposure related to a commercial product, the product label should be read carefully and, if necessary, the manufacturer contacted to obtain information about what chemicals the product contains. For products used at work, identification of chemical constituents often begins with Material Safety Data Sheets (MSDS); employers are required to keep MSDSs on file for all products that could be harmful. Once the chemicals in a product are identified, the local poison control center or Web-based information systems can aid in confirming the diagnosis of chemical toxicity and managing the resultant illness.

The next step is to perform a complete history and physical examination to exclude other possible etiologies. Remember, patients with chronic diseases resulting from other factors (e.g., coronary artery disease, hypertension, or tobacco-related COPD) can have their diseases exacerbated by their occupational and living environments and control of aggravating exposures can improve outcomes.

If there is a concern about work-related respiratory illnesses, such as asthma or hypersensitivity pneumonitis,

documentation of work-related variability in symptoms or lung function is important to link exposures to effects. Exposures to certain heavy metals or pesticides can be confirmed by biomarkers of exposure (e.g., blood lead or acetylcholinesterase levels).

Finally, it is important to ascertain whether other people who spend time in the home or workplace are also ill in order to identify and reduce high-risk exposures to prevent further spread of illness.

OCCUPATIONAL INJURY

When caring for a patient who has been injured at work, the goals are to minimize time out of the workforce and long-term physical disability, and prevent future serious or even fatal injuries. If the patient is unable to return to work because of the injury, he or she should be referred to an occupational medicine specialist. There the patient can receive rehabilitation care, safety training, ergonomically improved job redesign, and assistance with workers' compensation and disability benefits, as needed.

Workers' compensation is a type of insurance system that is usually governed by state- and nation-specific rules. In general, workers who become injured or sick because of work-related factors are entitled to reimbursement of lost wages and for any permanent disability. The historical compromise that allowed the workers' compensation system to be developed was speedy payment of benefits to injured workers with the proviso that they gave up their right to sue employers for liability. The current system in the United States does not always live up to either side of this bargain: benefit payments often are delayed because of litigation. Most physicians are inadequately prepared to deal with the separate and somewhat arcane workers' compensation reporting rules and billing procedures. Perhaps the most important point for nonoccupational medicine physicians to remember is that their patients who are injured or made sick at work will likely need expert help (medical and/or legal) at navigating the workers' compensation system in their state.

ENVIRONMENTAL ILLNESS

When caring for a patient who is exposed to a hazardous living environment, therapeutic interventions tend to be more complex because the living environment is created by a complex interaction of people, organizations, and physical factors (i.e., architects, planners, landlords, bus depots, industrial sites) (see Chapter 8). The type and extent of assistance will depend on whether the concern is removing lead paint from the walls or decreasing community violence. Health-care professionals can serve as a bridge to connect individuals at risk with community organizations, governmental regulatory units, and legal professionals who work with vulnerable populations to promote environmental justice.

For example, if poor housing has been identified as a health risk, national agencies such as the EPA and the US Department of Housing and Urban Development (HUD) have Web-based information systems and hotlines to help patients and clinicians know how and where they can get the safety of the drinking water or soil at their homes checked or paint tested for lead. Health-care providers may advocate for interventions from repair of water damage to reduce mold to improved appliances to reduce indoor air pollution, or more radically the patient may need to be relocated to a healthier unit.

If outdoor urban air pollution has been identified as the health risk, then patients should be instructed on how to access daily air pollution reports from local news sources or Web-based systems. Possible interventions that can be advocated include minimize outdoor activities during high pollution periods or traffic rush hour if living near busy roadways, attend planning meeting to voice opposition to the construction of new toxic waste sites or industrial refineries near populated communities, and, in severe cases, the patient may have to relocate to a less polluted neighborhood or city. Interventions to make communities safer require that patients and health-care providers direct their efforts toward local governmental and community organizations focused on these issues.

REPORTING REQUIREMENTS

Occupational injuries and illnesses generally are required to be reported by employers, but not usually by physicians. In California, physicians are required to report diagnoses of occupational injury or illness on a standard form. Elevated blood lead levels in children and often in adults must be reported in most states, but this requirement usually falls to the clinical laboratory doing the measurement rather than the physician who ordered the test. Several states (e.g., California, Washington, Texas) also require reporting of pesticide-related illness.

PUBLIC HEALTH, URBAN PLANNING, AND COMMUNITY-BASED RESEARCH

The disproportionate exposure of ethnic and racial minorities to dangerous occupations and harmful environments is caused by complex interactions of economic, social, and political factors. It is crucial that politicians, urban planners, developers, architects, and engineers recognize the link between these factors and the physical environment in which our patients live and work.[14,17,29]

In 2009, the CDC published the Healthy Community Design Expert Workshop Report, which argued that

healthy community design is fundamentally linked to public health and that collaboration between health professionals with community and transportation planners, architects, and developers is vital to advancing these goals.[62] "Smart growth," which takes into account the potential health consequences of land-use decisions, was recommended. For example, enhancing community "walkability," with more sidewalks, open spaces, and safety, promotes exercise and better general health. In contrast, "sprawl," and poorly planned growth, increases use of motor vehicles, air pollution levels, and poor respiratory health.

Health-care providers caring for vulnerable populations can advocate for their health by participating in community development and by providing strong public health arguments to support or oppose planning proposals (see Chapter 8).[22] Providers are also able to identify areas where research is needed to better understand the associations between exposures and health as well as assessing the potential health impacts of environmental and occupational interventions.[19]

CONCLUSION

The ultimate treatments for the heavy burden of occupational and environmental illness borne by the poor are preventive interventions occurring at a community or societal level, that is, policy changes to promote full employment, occupational health and safety, environmental justice, and smart growth. Clinicians also have a role to play in preventing, recognizing, and mitigating their effects and advocating for long-term solutions.

Environmental and Occupational Safety

Take a work and residential history.

Refer to an occupational health specialist when:

- Patients' job-related injuries keep them from working to assist with job redesign, safety training, disability evaluation, and workers' compensation
- For patients with pulmonary problems living in a polluted neighborhood or substandard housing for home environment assessment

Know your community

Environmental justice organizations

- Local polluting sources
- Waste facilities
- Crime statistics
- Availability of open spaces and recreation parks
- Neighborhood resources for healthy choices

Be alert to the connection between environment and health

Advocate for patients on the community level

How to Obtain a Home Assessment

1. Contact your local health department. Most health departments in large cities have environmental health units that may be able to provide inspections of the housing conditions of patients for whom there is a high suspicion of illness related to home environmental exposures. If such personnel are not available, contact an occupational health clinic for assistance in arranging for an industrial hygienist to inspect the home.
2. Document the conditions. Either the specialists or a member of the primary health team can visit the home to document the presence of poor housing conditions or the patient should take photos of the damage.
3. Consider a therapeutic trial of changing residence. If the inspection warrants it, try changing the environment (e.g., temporarily living with a relative) and following clinical status. If symptoms improve, then efforts to provide a more permanent change in residence are warranted.

DISCUSSION QUESTIONS

1. A 22-year-old man, who is a recent immigrant from Mexico, comes to your office complaining of back pain. What are the important occupational issues that should be discussed at this visit and what interventions would you suggest?
2. A 32-year-old African-American woman who you follow up for severe persistent asthma comes to your office after three emergency room visits in the past month. What are the important work and home environment issues that should be discussed and what interventions would you recommend?
3. The city is proposing to expand a highway to lessen traffic congestion and improve commute times. The highway expansion is to occur through one of the poorest sectors of town. Will this affect the health of the local community? What can you do to make your opinions heard?
4. Using Web-based resources, look up the following questions: My apartment is flea infested. I have a 6-month-old child, can I safely have the place flea bombed? Every time I turn on the heat in the house I get a headache. Could there be a problem with the heater?

RESOURCES

The National Institute for Occupational Safety and Health Web site provides information on specific hazard, occupation, or disease. http://www.cdc.gov/niosh/topics/.

The Children's Environmental Health Network is a national multidisciplinary organization whose mission is to protect the

developing child from environmental health hazards and promote a healthier environment. http://www.cehn.org.

The World Health Organization Web site provides information on a variety of environmental and occupational hazards that affect human health. http://www.euro.who.int/en/health-topics/environment-and-health.

The US Environmental Protection Agency Web site provides links to local air quality data, resources to aid in patient education and care regarding health effects of air pollutants. http://airnow.gov/.

The Healthy Homes Program Web site of the US Department of Housing and Urban Development provides links to useful documents such as "Overview of Asthma and the Home Environment" and "Help Yourself to a Healthy Home." http://www.hud.gov/offices/lead/hhi/index.cfm.

The Web site of the Association of Occupational and Environmental Clinics provides contact information for clinics throughout the United States. http://www.aoec.org/.

The National Association of City and County Health Officials has a searchable Web site with useful information on environmental health and justice. http://www.naccho.org/.

The U.S. Centers for Disease Control and Prevention's Division of Community Health has a Web page with resources that can be used to improve the health of communities. http://www.cdc.gov/NCCDPHP/dch/resources/index.htm.

The U.S. Environmental Protection Agency has a program to improve the ability of health-care providers to recognize pesticide exposures and manage pesticide-related health problems called the "National Strategies for Health Care Providers: Pesticide Initiative." http://www.epa.gov/oppfead1/safety/healthcare/handbook/handbook.pdf; http://www.epa.gov/pesticides/safety/healthcare/healthcare.htm.

The World Health Organization has a program to set norms and standards for pesticide use to protect public health. http://www.who.int/whopes/en/.

The U.S. Centers for Disease Control and Prevention has a "National Action Plan to Prevent Childhood Injuries." http://www.cdc.gov/safechild/NAP/toc.html.

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Chapter 26

Care of the Food Insecure Patient

Hilary K. Seligman, MD, MAS and Jonas Z. Hines, MD

Objectives

- Contrast food insecurity and hunger.
- Discuss coping strategies associated with food insecurity that complicate disease management.
- Identify risk factors for food insecurity and describe its epidemiology.
- Discuss the nutritional, behavioral, and mental health impacts of food insecurity.
- Identify challenges to providing care to food insecure patients and strategies that can help address these challenges in the clinical setting.

Ms. Walker is a 48-year-old woman with a history of diabetes, hypertension, obesity, and depression. Her last hemoglobin A_{1c} was 9.0%. She seems poorly engaged with her diabetes care, taking her medications intermittently, and infrequently adhering to a diabetic diet. She tells you that she frequently has difficulty making ends meet. Sometimes, rice is the only food she can afford to eat. You suspect her food insecurity is complicating her diabetes management.

INTRODUCTION

Food insecurity, or the inability to reliably access safe and nutritious food, has important health consequences. Food insecurity has an impact on health through nutritional, behavioral, and mental health pathways. Food insecure children and adults have higher rates of acute and chronic illness and higher health-care utilization. Management of chronic, diet-sensitive diseases, such as obesity, diabetes, and congestive heart failure, is particularly challenging in the context of food insecurity. This chapter explores the complicated relationships between food insecurity and illness with a focus on the issue in the United States and presents strategies to improve the care of food insecure patients.

DEFINITION AND PATTERNS OF FOOD INSECURITY

The most commonly accepted definition of food security and food insecurity comes from a 1990 report by the Life Sciences Research Office (LSRO)[1]:

> Food security was defined … as access by all people at all times to enough food for an active, healthy life and includes at a minimum: a) the ready availability of nutritionally adequate and safe foods, and b) the assured ability to acquire acceptable foods in socially acceptable ways (e.g., without resorting to emergency food supplies, scavenging, stealing, and other coping strategies). Food insecurity exists whenever the availability of nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially acceptable ways is limited or uncertain.

In the United States, food insecurity generally implies that access to adequate food is limited by a lack of money and other resources. Globally, food insecurity may be due to other factors such as political unrest. The United Nations' Food and Agriculture Organization defines food security as existing "when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life." Food must be consistently available, accessible, and useable.[2]

DISTINGUISHING FOOD INSECURITY AND HUNGER

Food insecurity is a concept distinct from the physical sensation of hunger. According to the LSRO,[1] "Hunger (in its meaning of the uneasy or painful sensation caused by a lack of food) and malnutrition are potential, although not necessary, consequences of food insecurity." Although the term "food insecurity" may obscure the tragedy of hunger, the term includes the coping strategies that households employ to avoid the physical sensations of hunger. Understanding these strategies makes clear the health and public health consequences of food insecurity (Box 26-1).

PATTERNS OF FOOD INSECURITY

Every year in the United States, the Department of Agriculture reports the prevalence of three categories of food security: food security, low food security, and very low food security.[3] Households with low or very low food security are considered "food insecure." In general, people living in households with low food security report difficulty accessing food and the need to reduce diet quality in order to compensate for inadequate food budgets, but typically have not reduced their quantity of food. People living in households with very low food security experience reductions in their food intake and disruption of their normal eating patterns because of a lack of money or other resources for food.

In the developed world, and often in the developing world as well, food insecurity is cyclic and episodic. That is, episodes of food adequacy are punctuated by discrete episodes of food scarcity because of particular economic stresses. Households may confront an episode of food scarcity resulting from a variety of life stressors: for example, periodic, unforeseen expenditures (such as an acute medical condition or a car repair); an increase in necessary household expenditures (such as the need for heating in the winter, or to feed children in the summer when school-based access to free or reduced-price lunch declines); or, predictably at the end of the month, if household income is not adequate to cover food requirements.[4]

The typical food insecure household in the United States experiences food scarcity during 7 months of the year, with each episode lasting for a few days.[3] The cyclic nature of food scarcity in the food insecure household and its resulting fluctuations in dietary intake make clinical care of food insecure patients with chronic disease particularly challenging.

Box 26-1. Food Insecurity Coping Strategies

Shifting dietary intake to low-cost, highly filling foods (such as refined carbohydrates).

- Reducing dietary variety.
- Binge eating and avoiding food waste when food is available.
- Skipping meals or reducing dietary intake when food is unavailable.
- Shopping strategies to improve the affordability of food (buying produce in season, using coupons, taking advantage of sales, etc.).
- Enrollment in federal nutrition programs (such as the Supplemental Nutrition Assistance Program (SNAP, formerly called "Food Stamps); the National School Lunch Program (NSLP); or the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).
- Utilizing the hunger safety net, which includes food pantries; soup kitchens; community dining; and less formal food support from religious institutions, friends, and family.

EPIDEMIOLOGY

In 2013, one in seven US households (or 14.3% of all households) reported food insecurity. These households included 33.3 million adults and 15.8 million children, of whom 12.2 million adults and 765,000 children lived in very low food secure households.[3] In safety-net outpatient institutions in the United States (such as Federally Qualified Health Centers), the prevalence of food insecurity often approaches 50%.

Worldwide, 842 million people (one-eighth of the world population) are estimated to be food insecure,[5] with the vast majority living in developing regions. As poverty has declined and food production increased over the past several decades, the global burden of food insecurity has declined (Figure 26-1).

RISK FACTORS FOR FOOD INSECURITY

Ms. Walker has two children at home and is divorced. She works the night shift in a 24-hour diner. She tells her primary care provider (PCP) that she has difficulty balancing her work with parenting. In particular, she is finding it difficult to purchase and prepare healthful food. When her food budget is particularly short, she serves her children first and eats herself only what is left over. She has recently started smoking again, which she says helps her cope with the stress.

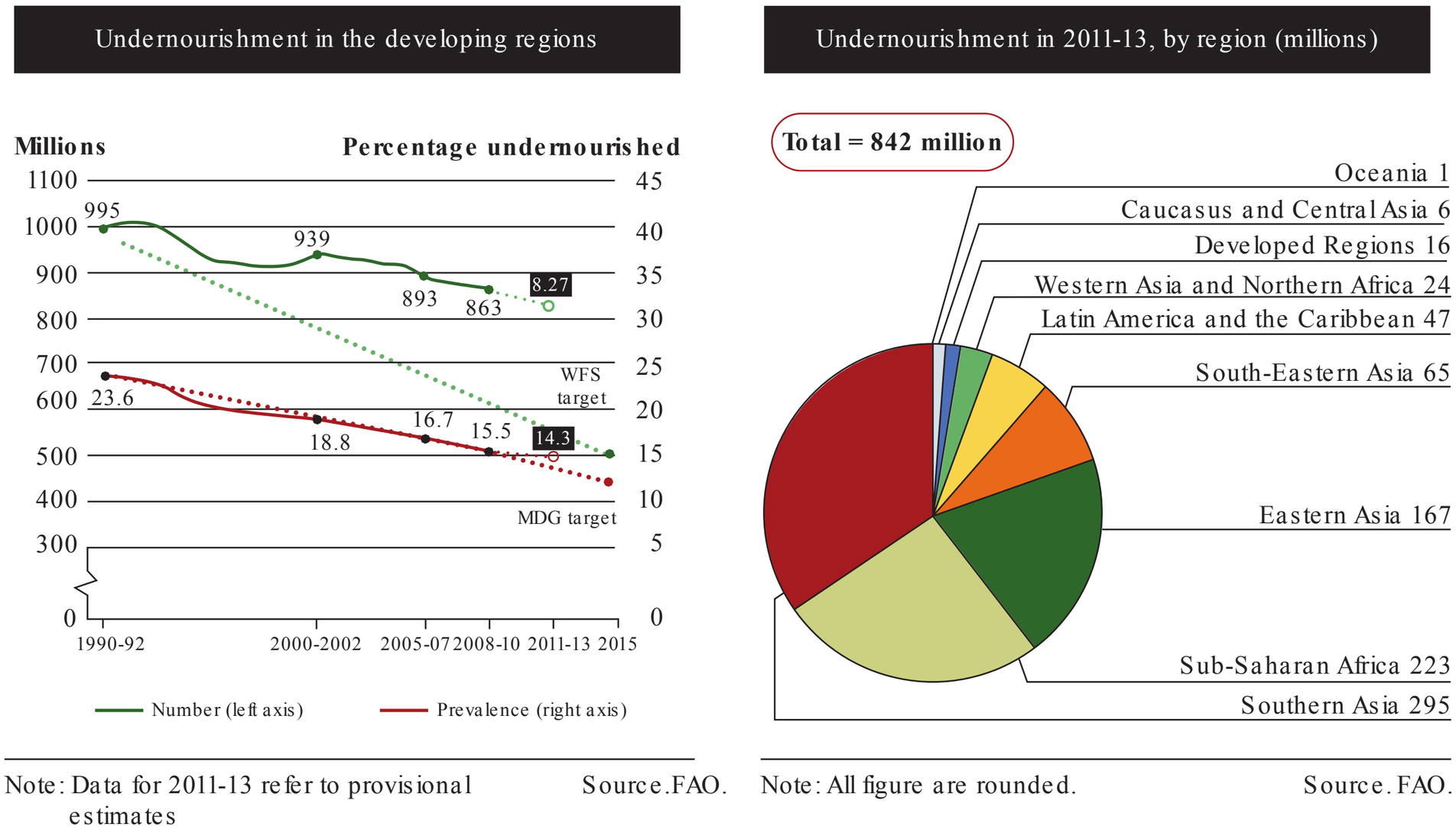


Figure 26-1. **Left:** Undernourishment in the developing regions: actual progress and target achievement trajectories toward the MDG and WFS targets. The estimated number of undernourished people has continued to decline; however, the rate of progress is insufficient to reach MDG and WFS goals for hunger reduction. **Right:** The changing distribution of hunger in the world: number and share of undernourished by region, 2011–2013. Overall, there has been a reduction in the number of undernourished people over the past two decades; different rates of progress across regions have led to changes in the distribution of undernourished people in the world. Most of the world's undernourished people are found in Southern Asia, closely followed by sub-Saharan Africa and Eastern Asia. MDG, Millennium Development Goal; WFS, World Food Summit. (Adapted from FAO, IFAD and WFP. The State of Food Insecurity in the World. The Multiple Dimensions of Food Security. Rome: FAO, 2013.)

The root causes of food insecurity are highly complex and include both personal vulnerabilities (individual risk factors) and structural factors.[6]

INDIVIDUAL RISK AND RESILIENCE FACTORS FOR FOOD INSECURITY

In the United States, the strongest risk factors for food insecurity include having children in the household, low household income, and racial/ethnic minority status (black or Latino).[1] Single-parent households are at the highest risk for food insecurity. More than a third of all households with children headed by a single woman in the United States are food insecure.

Although poverty is highly associated with food insecurity, it is not synonymous with food insecurity. Almost 60% of households with incomes below the US federal poverty level in 2012 did not report food insecurity, while almost 7% of households with incomes greater than 185% of the US federal poverty level did report food insecurity.[1] Food insecure households are more likely to have experienced a recent event stressing the household budget, such as loss of employment, addition of a household member, or reduced access to federal nutrition benefits.[2,7] In addition, some households have specific financial obligations that drain money from food budgets. For example, many immigrant households regularly send money to their country of origin to support family members (see Chapter 29). Other households must shoulder high out-of-pocket health-care expenditures.

Food insecure households report difficult financial choices between paying for food and paying for health care, utilities, transportation, housing, and education. Why are these necessities frequently prioritized over food? First, money that might otherwise be saved for food purchases in the near future are often deferred to other needs because food expenditures can be spread throughout the month. Second, the presence of a safety net for food (relatives/friends, food pantries, etc.) may allow for prioritization of other expenses. Finally, the ability to reduce food budgets by reducing food quality allows flexibility in the food budget that is not present in other parts of the budget.

Mental illness, tobacco use, and chronic illness place people at risk for food insecurity. Mental illness is tightly

associated with food insecurity across the lifespan. It is likely that this relationship is bidirectional. In other words, food insecurity predisposes people to mental illness through both stress and micronutrient deficiency pathways; at the same time, mental illness predisposes people to food insecurity through its impact on employability and high-level executive function. The association between mental illness and food insecurity has been well documented among children, adolescents, pregnant women, adults with chronic illnesses (such as diabetes), and the elderly.

Tobacco use by any person in the household predisposes the entire household to food insecurity, both in the United States and globally.[1] This "crowding out effect," in which food income is used to purchase tobacco, is likely to impact households with a family member using illicit substances as well, although this area has been inadequately studied.[8,9]

The prevalence of diabetes, hyperlipidemia, and hypertension are all higher in food insecure households than in low-income households that are not food insecure.[3] Members of food insecure households that include chronically ill members often choose between paying for food and paying for health-care expenses. For example, two-thirds of food pantry clients in the United States report having to choose between buying food and medical care.[10] These competing demands help explain the high rate of medication nonadherence observed in food insecure households.[11-13]

There are also factors that protect families against food insecurity even in the context of poverty. Although enrollment in federal nutrition programs such as SNAP is not adequate to pull many households out of food insecurity, they do reduce the depth and duration of food scarcity episodes. Financial skills (such as managing bills, making a budget, stretching groceries), knowledge of community resources for food assistance, and cooking skills also protect against food insecurity.[14]

STRUCTURAL FACTORS INFLUENCING FOOD INSECURITY

Policies that reduce the need for high expenditures in other parts of the budget allow households to avoid food insecurity. In the United States, for example, states with high food insecurity rates also have low average wages and high unemployment, high housing costs, low participation in federal nutrition programs, and a high tax burden on low-income households.[15] Policy changes that relieve the budgets of poor households (e.g., access to affordable housing and health care, livable minimum wage) are likely to reduce food insecurity rates.

Besides these economic factors, ecological factors are also important drivers of food insecurity.[6] For example, drought, flooding, and other natural disasters can have important consequences for food prices and regional food availability, particularly in the developing world. Political instability and social unrest can have an acute impact on food prices and food availability, and chronically undermine food availability by reducing investment in agriculture. Finally, the volatility of food prices affects the degree to which the poor, in particular, are able to access food.

FOOD INSECURITY AND ILLNESS

> Ms. W. visits the emergency department with a blood glucose level of 45 mg/dL and has multiple other episodes of hypoglycemia not requiring emergency department management. She is not regularly checking her blood sugars because she cannot afford the testing strips, but when she does her blood sugar is generally >250 mg/dL. Her weight has increased eight pounds in the last 12 months. Today, her primary concern is ongoing headaches.

For decades, the adverse effects of food insecurity on the physical, emotional, cognitive, and intellectual development of children has been appreciated. Many of these effects have been attributed to dietary micronutrient deficiencies. For example, food insecure mothers are more likely to be deficient in iron and folate, which is linked to adverse fetal outcomes at birth and throughout the lifespan. Children living in food insecure households are more likely to develop iron deficiency, which impacts cognition, attention, and behavior even after treatment.[16] Only more recently has the health impact of food insecurity for adults been recognized.

Three pathways likely drive the relationship between food insecurity and acute and chronic illness in children and adults: nutritional, behavioral, and mental health (Figure 26-2). Once a food insecure child or adult becomes chronically ill, competing demands place further stresses on food budgets creating a cycle of worsening food insecurity and chronic illness.

Food insecurity is thus a concern for medical providers not only because it predisposes people to acute and chronic illness, but also because acute and chronic illness predisposes households to food insecurity. It is in the context of diet-sensitive chronic diseases, such as obesity, diabetes, hypertension, and congestive heart failure, that food insecurity presents the greatest challenges. Coping strategies that allow people to avoid the physical sensation of hunger may be adaptive in the short term, but when maintained over years or decades they predispose adults with diet-sensitive chronic disease to poor disease control and ultimately increased risk of complications. These complications result in additional health-care expenditures and low employability, which further strain food budgets.

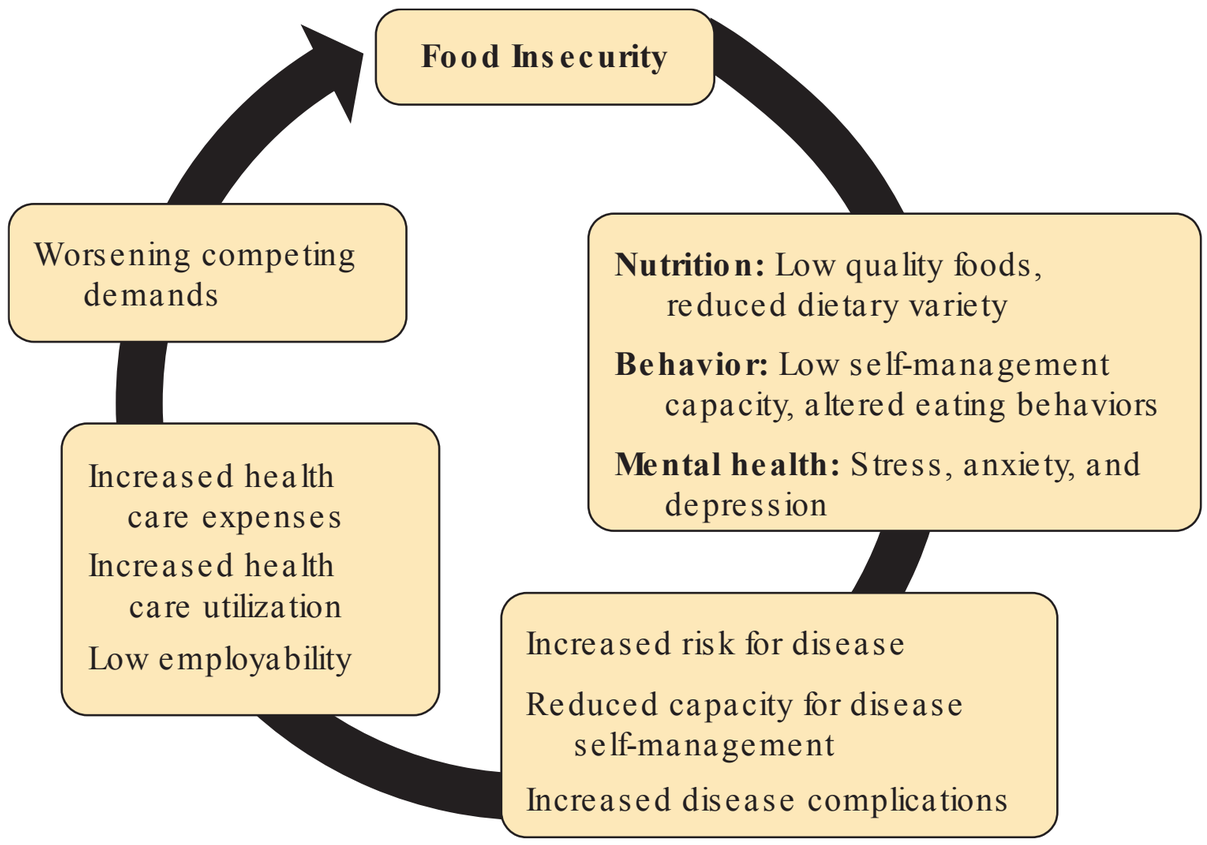


Figure 26-2. Cycle of food insecurity and chronic disease. (Adapted from Seligman HK, Schillinger D. Hunger and socioeconomic disparities in chronic disease. N Engl J Med 2010;363:6-9; and Weiser SD et al. Conceptual framework for understanding the bidirectional links between food insecurity and HIV/AIDS. Am J Clin Nutr 2011;94:1729S-1739S.)

These coping strategies also explain why food insecurity is associated with both under- and over-nutrition.

NUTRITIONAL IMPACT OF FOOD INSECURITY

Dietary intake among people living in food insecure households is poorer than dietary intake among individuals in food secure households.[17] The diets of food insecure adults tend to be lower in vegetables, fruit, dairy, and some micronutrients than the diets of food secure adults, while the diets of food insecure children are lower in fruit than the diets of food secure children. The relatively better diets of food insecure children compared to food insecure adults may reflect the capacity of adults in the household (particularly mothers) to buffer the impact of food insecurity on children in the household by more heavily altering their own dietary intake.[18] Much qualitative data document the sacrifices household adults make to ensure children have access to sufficient calories of the highest possible quality. However, even in households where the children are presumably shielded, children still seem to suffer adverse health consequences, potentially mediated by the high levels of stress, which accompany household food insecurity.

The average American household in the lowest income quintile already expends more than a third of their annual income on food.[18] A diet recommended by the US Department of Agriculture (including five servings of fruits and vegetables daily) would require the average low-income family to spend 43–70% of their entire food budget on fruits and vegetables, leaving little left over for protein, dairy, and grains.[19] Calorie for calorie, the cheapest foods in the United States include oil, shortening, margarine, sugar, bread, pasta, and rice.[20] Moreover, in the last three decades, the prices of fruits and vegetables have become more expensive compared to other foods.[21] Substituting healthy foods with saturated fats and sugar significantly reduces food costs.[22] If one's goal is to maximize caloric intake for the cheapest amount of money in anticipation of future food shortage, adhering to a healthful diet may be a luxury.

Although it is possible to eat healthy and nutritious foods on a very low budget, medical providers must recognize other barriers to healthy dietary intake in this population. Barriers perceived as additional "costs" to healthy dietary intake include the availability of equipment for food storage and preparation (i.e., it is challenging to prepare raw foods if the utilities have not been paid, or a family is living in a car or a homeless shelter), time to travel to stores which stock a variety of healthy foods that are of acceptable quality, and time to prepare nutritious foods (e.g., raw fruits and vegetables). Although the average US household spends 4.4 hours weekly on food production, eating on a Thrifty Food Plan budget requires an average of 13.1 hours weekly; that means to eat a healthy, very low cost diet requires more than one additional hour per day of food preparation (US Department of Agriculture defines a nutritious diet at four different price points. The Thrifty Food Plan is the lowest cost of these plans, followed by the Low-Cost, Moderate-Cost, and Liberal Food Plans).[1,23] Institutions that provide free or reduced cost food as part of the hunger safety net are subject to these same pressures, forcing food pantries, soup kitchens, and school-based meal programs to reduce the quality of the meals they provide as well. Therefore, relying on the hunger safety net does not consistently alleviate the poor nutritional intake associated with food insecurity.

Erratic dietary changes associated with food insecurity are one likely reason that food insecurity among women is associated with obesity. Food insecurity may also be associated with obesity among children and men, although this evidence has been far less consistent.

Food insecurity is also associated with the development of type 2 diabetes, gestational diabetes, and poor diabetes outcomes.[24-27] For example, food insecure patients receiving care for diabetes in safety-net clinics report more difficulty following a diabetic diet, poorer dietary intake, and higher hemoglobin A_{1c} values than food secure patients in the same clinics. Changes in dietary intake observed among patients with diabetes help explain the poor glycemic control observed in this population.[28,29]

Highly processed foods are cheap and shelf-stable, so they are often relied on for calories during episodes of food scarcity. In addition, highly processed foods generally contain high levels of sodium in order to boost flavor, improve the appearance of key ingredients (such as vegetables in soup), and preserve freshness. High sodium intake during episodes of food scarcity may impact management of hypertension and congestive heart failure.

BEHAVIORAL IMPACT OF FOOD INSECURITY

Much of the behavioral impact of food insecurity (low self-management capacity, altered eating behaviors) is driven by its cyclic and episodic nature, as described earlier. Episodes of food scarcity are sometimes, but not always, predictable. For example, an unexpected cold snap will drive down food expenditures in low-income, but not higher-income, households as food budgets are diverted to home fuel costs.[30] The pent-up demand for food when money becomes available is evident, for example, by increases in grocery store purchases at the beginning of the month.

Women who restrict their dietary intake when food is less available and then "make up for it" when food becomes available—the so-called feast or famine phenomenon—are at high risk for obesity. In turn, maternal obesity is a risk factor for childhood obesity. Adolescents living in food insecure households are more likely to exhibit similar "feast or famine" eating behaviors, such as binge eating.[31] Other behaviors common in food insecure households include food hoarding and a reluctance to try new foods, which, if not consumed, drain the family food budget.

In the context of diabetes, such fluctuations in the availability of food are even more challenging to manage. Although on average food insecure patients with diabetes have higher hemoglobin A_{1c} values, they also report more episodes of severe hypoglycemia and more emergency department visits for hypoglycemia.[32] In fact, in California, inpatient admissions for hypoglycemia increase by 27% in the last week of the month (when food budgets are most likely to be exhausted) compared to the first week of the month, but only in low-income zip codes.[4] If providers do not recognize food insecurity as the etiology of the hypoglycemia, the typical clinical response is to reduce oral hypoglycemia medication or insulin. Such management exacerbates the poor glycemic control associated with food insecurity, whereas strategies that support patients in reaching food security address the hypoglycemia without sacrificing glycemic control.

MENTAL HEALTH IMPACT OF FOOD INSECURITY

Food insecurity is associated with mental health across the lifespan, with higher risk of depression, anxiety, and behavior disorders. In addition to diagnosable mental illness, food insecurity is highly stressful. Food is a basic physiologic requirement; if unavailable, it will dominate one's cognition and behavior (a concept articulated in Maslow's Hierarchy of Needs[33]), reducing bandwidth available for other important tasks such as parenting children, maintaining employment, registering or re-registering for benefits, and managing chronic illness.

For people with diet-sensitive chronic disease, food insecurity adds an additional layer of stress to diabetes self-management. Overall, food insecure adults with diabetes report lower confidence in their ability to manage their diabetes and greater emotional distress related to their diabetes.

> Ms. Walker discloses that she frequently is skipping meals to save money but takes her medications most days of the week. Although she is enrolled in Medicaid, she is not enrolled in a nutritional assistance program. She is motivated to quit smoking.

STRATEGIES FOR ADDRESSING FOOD INSECURITY IN THE CLINICAL SETTING

Providers should routinely screen selected populations for food insecurity, including patients with obesity, diabetes, weight loss, vague abdominal complaints (especially children), and mental illness (Box 26-2). In addition, providers should screen patients in safety-net settings and households with children (see "Core Competency"). Some patients feel stigmatized by their inability to support the food needs of themselves or their family; providers must therefore pay particular attention to addressing food insecurity nonjudgmentally. Providers may need to use many approaches to address food insecurity in the clinical setting.

REFERRALS

Emphasize that adequate access to nutritious food is critical for maintaining health. Many adults are reluctant to access the hunger safety net, but reframing the issue as a

Box 26-2. Common Pitfalls

Health-care providers do not regularly incorporate food insecurity into patient care

Risk factors FOR food insecurity
- Low income
- Minority status
- Single-parent household
- Children in the household
- Chronically ill household members
- Smoking
- Substance use
- Political unrest/natural disasters

Protective factors
- Cooking skills
- Financial management skills
- Access/knowledge of resources
- Living in areas with a stronger hunger safety net

Risks OF food insecurity
- Worse outcomes in almost every medical condition studied

Short list of common problems associated with food insecurity:
- Obesity
- Diabetic complications of poor glycemic control AND hypoglycemia
- Development of gestational diabetes
- Nutritional deficiencies leading to low birth weight; intellectual and emotional difficulties in children
- Anemia
- Stress
- Poor medication adherence

health priority may encourage people to take advantage of existing resources. Consider whether your patient might be eligible for SNAP, WIC, or home-delivered meals. Congregate meal sites for seniors are sometimes available. Encourage use of food pantries when budgets are tight.

COUNSELING

Food insecure households face many challenges in making dietary substitutions. Providers who do not recognize the profound barriers patients face to medication and dietary adherence may inadvertently cause and/or exacerbate this low confidence and distress by repeatedly revisiting, emphasizing, and insisting on behavior changes that seem impossible to attain.

Provider counseling that includes only budget-neutral strategies for behavioral change may partially alleviate this distress (see Chapter 12). For example, emphasizing portion control rather than dietary substitutions may be a more effective strategy for initially engaging food insecure patients in self-management. For Ms. Walker, reducing her portion size of rice from one cup to half cup is more achievable than increasing her vegetable intake. Once a patient is engaged in the process of behavior change, then dietary substitutions can be addressed.

MEDICATION MANAGEMENT

Medication management is most important for food insecure patients with diabetes. To avoid hypoglycemia, counsel patients to use oral hypoglycemic and insulin only with meals (rather than at a certain time of day) in order to avoid the hypoglycemia that accompanies an unexpectedly missed meal. When using oral hypoglycemic medications such as sulfonylureas, use those with the shortest half-life to reduce the risk of hypoglycemia. Patients should also reduce medication doses on days when food access is unpredictable.[36]

Food insecurity has important implications for medication adherence as well. Because of competing demands, food insecure patients may put off taking their medications in order to purchase food or may put off buying food in order to pay for medicines. Among food insecure patients with diabetes, limited ability to afford testing strips may also contribute to the increased risk of hypoglycemia.

Review out-of-pocket health-care expenditures with food insecure patients and assist patients to minimize them. Patient assistance programs may be one avenue to explore for patients facing difficulty affording medicines or supplies.

SMOKING AND SUBSTANCE ABUSE

Because nicotine acts as an appetite suppressant, food insecure patients may have a particularly difficult time with smoking cessation (see Chapter 40). Smoking cessation in this population is important, however, not only to mitigate the adverse health effects associated with smoking but also because it relieves food budgets (for the smoker and the rest of the household), which in turn may allow for more healthy food purchases.

Use of alcohol and other illicit substances similarly drains food budgets (see Chapter 39). Therefore, smoking cessation and substance abuse treatment are important components to addressing food insecurity.

POLICY AND ADVOCACY

Physicians can be strong voices for policies that support food security in their local communities (see Chapter 8). Suggestions for local advocacy efforts to enhance food security include improving school meals; access to SNAP, WIC, and other nutritional benefits programs; supporting the hunger safety net; and supporting policies that benefit low-wage earners. Schools provide an excellent opportunity to reach children and adolescents with nutrient-dense foods and to model healthy eating practices. Policies that improve the nutrient content of school meals, encourage more low-income children to participate in school meals, and maintain school meal access through vacation periods can have a substantial impact on relieving food budgets at home.

Although many states have enrolled most people eligible for SNAP, WIC, and other nutrition benefits programs, some states have very low participation rates. For example, California, Colorado, Hawaii, Kansas, New Jersey, Nevada, Texas, and Wyoming each have very low rates of SNAP participation. Physicians can advocate for reaching those who are left out. These families often have language barriers, mistrust of the government, or some household members being undocumented.

The United States has a system of food banks, food pantries, soup kitchens, and community dining programs that are essential sources of food support for food insecure families. Inadequately funded programs must rely on cheap, nutrient-poor foods. Advocating for adequate funding can improve the availability of healthy foods available in the hunger safety net. Finally, supporting policies for low-wage earners such as increasing the minimum wage, housing assistance, and enhancing other areas of the safety net will increase well-being overall for poor families, not the least by increasing the budget for food.

CONCLUSION

Food insecurity is highly prevalent in the United States and has important implications for both the development and management of disease. Addressing food insecurity in the clinical setting may improve chronic disease self-management and reduce stress. Enrollment in federal nutrition programs may be the single most effective strategy for reducing food insecurity among patients. These programs are targeted at low-income households, with specific programs targeting vulnerable populations such as children, seniors, and pregnant or postpartum women. The three largest federal food and nutrition assistance programs are the SNAP, the WIC, and the National School Lunch Program (NSLP).[10] However, policy-level solutions are required for more broadly addressing food insecurity.

- Food insecurity is a medical issue.
- Food insecurity can cause illness and make illness more challenging to manage.
- The food insecure patient with diabetes faces the most acute challenges and risks.
- Providers should tailor medication regimens and dietary counseling for all food insecure patients, particularly in the context of diabetes.
- Enrollment in federal nutrition programs may be the single most effective strategy for reducing food insecurity among patients.
- Policy solutions for addressing food insecurity are necessary for more broad scale reductions in food insecurity rates.

Addressing Food Insecurity in the Clinical Setting

Screen for food insecurity:

- Screen for food insecurity, particularly in the following clinical scenarios—obesity, diabetes, hypertension, congestive heart failure, weight loss, vague abdominal complaints (particularly among children), and mental illness. All patients in safety-net settings and all households with children should be screened.

Screening suggestions

- I'm going to tell you two statements that people have made about their food situation. Please tell me whether the statement was often true, sometimes true, or never true for (you/your household) in the last 12 months—that is, since last (name of current month).
  - The first statement is "(I/We) worried whether (my/our) food would run out before (I/we) got money to buy more." Was that often true, sometimes true, or never true for (you/your household) in the last 12 months?
  - The second statement is "The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more." Was that often, sometimes, or never true for (you/your household) in the last 12 months?
- An "often" or "sometimes true" response to either question has a 97% sensitivity and 83% specificity for food insecurity in households with children.[34,35]

Tailor dietary counseling:

- Emphasize portion control over dietary substitutions.
- Where dietary substitutions are necessary, make cost-neutral recommendations.
- Discuss cost-effective strategies for affording healthy foods: enrolling in federal nutrition programs to supplement food budgets, buying fresh fruits and vegetables in season or frozen, and shopping at farmers markets.

Research hunger safety-net options in your community:

- What percentage of food provided by the local food bank is healthy food?
- Does your community have access to community dining programs for seniors?
- Home-delivered meals for the elderly or homebound?
- How do you enroll in SNAP, WIC, or the NSLP in your community?

Appropriately manage oral hypoglycemic medications and insulin for food insecure patients with diabetes:

- If you must use oral diabetes medicines, which can predispose to hypoglycemia, limit risk by prescribing medications with a short half-life.
- Counsel patients to reduce or eliminate diabetes medications when access to food is unreliable. Although many patients understand the concept of reducing medications for a "sick day," many food insecure patients are not aware that this same principle applies for days when food access is reduced.
- For medications that can predispose to hypoglycemia, label prescription bottles to be taken with meals, rather

than at a time of day, in order to emphasize the importance of having access to food, for example, "glipizide 10 mg with breakfast and dinner" rather than "glipizide 10 mg twice daily."

Screen for use of tobacco or illicit substances:

- These behaviors reduce food budgets dramatically (see Chapters 39 and 40). Initiate appropriate counseling, treatment, and referrals. Remember that the appetite suppressant effects of some of these substances, particularly tobacco, complicate cessation attempts.

Assess for other indicators of malnutrition:

- Among the elderly, it is important to assess indicators that include chewing or swallowing difficulties; loss of appetite; alcohol use; eating alone; and physical challenges in shopping, cooking, or feeding oneself. Some validated screeners are available (see Chapter 23).
- Review out-of-cost expenditures for health care. Try to minimize out-of-pocket health-care expenditures by, for example, adhering to medication formularies, providing 3-month supplies of medication when copayments are unavoidable, and combining medical visits where allowable to reduce copayment burdens.
- Refer the patient to a social worker and benefits counselor to address whether he or she is receiving all allowable nutrition services and benefits.
- Refer to a nutritionist for additional assistance with dietary counseling.
- Acknowledge and address competing priorities that might affect self-management capacity.
- Advocate for systems changes that can help reduce burden of food insecurity (see Chapter 8).

DISCUSSION QUESTIONS

1. Discuss the difference between food insecurity and hunger. Can you explain how food insecure persons may adapt their behaviors to avoid hunger?
2. Imagine you work in a clinic that takes care of vulnerable populations. How might you incorporate screening questions for food insecurity into your clinic workflow? Are there particular groups of patients you would focus on? If so, who? What recommendations you would make to a patient who is food insecure?
3. Describe how food insecurity can lead to a downward spiral of overall health.

RESOURCES

Feeding America: www.feedingamerica.org.

United States Department of Agriculture, Economic Research Service: http://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us.

Food and Agriculture Organization of the United Nations: www.fao.org.

Food Research and Action Center: Frac.org.

Children's Health Watch: www.childrenshealthwatch.org.

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Chapter 27

Clinical Care for Persons with a History of Incarceration

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Objectives

- Explore the causes and scope of global mass incarceration.
- Identify socioeconomic and health disparities in individuals with criminal justice involvement.
- Recognize the impact of criminal justice system involvement on health outcomes and care delivery.
- Develop skills to prevent incarceration and mitigate effects of criminal justice system involvement on patients and families.
- Appraise evidence-based interventions to improve health outcomes and reduce recidivism in individuals with a history of incarceration.

Mr. Clark, a 54-year-old man who was released from prison 3 weeks ago, has visited the emergency department several times for suicidal ideation and atypical chest pain. He is also homeless.

INTRODUCTION

In the United States, 1 in 35 adults have been incarcerated and 1 in 43 children have a parent who is currently in prison—each year, more than 650,000 people are released from prisons and more than 7 million individuals are released from jails in the United States. Consequently, as a health-care provider, you are more likely to care for a patient who has been incarcerated or a patient whose parent has a history of involvement with the criminal justice system than you are to care for a patient who has sickle cell disease, cystic fibrosis, or type 1 diabetes (Box 27-1). Yet, health-care providers receive little training about this vulnerable population. Individuals who have been incarcerated disproportionately suffer from chronic illness, live in poverty, and face social marginalization—all of which are risk factors for and result from incarceration. The consequences of incarceration reverberate into patients' families and neighborhoods, impacting community health and well-being.

This chapter highlights the global prevalence of incarceration and the demographics and health disparities of individuals with a history of incarceration. Additionally, it discusses how criminal justice system involvement can confer vulnerability to an already at-risk population through inadequate medical care and suboptimal living conditions in prisons, barriers to health-care access upon release, and the collateral consequences arising from marginalization of those with a criminal record. Finally, it presents evidence-based interventions to reduce the health impacts of incarceration, and decreases risk of recidivism upon release.

Box 27-1. Criminal Justice Terms

- Jails: local correctional facilities that detain individuals awaiting trial or those sentenced to less than 1 year, increasingly, some states allow longer sentences.
- Prisons: federal or state correctional facilities that detain individuals found guilty of felony crimes and those who have sentences longer than 1 year.
- Parole allows a convicted individual to serve the remainder of a prison sentence in the community, often under supervised release.
- Probation is a period either immediately post-release from jail or in lieu of detention, when an individual is supervised in the community by a criminal justice officer and faces greater penalties for criminal activities.

Collectively these terms describe involvement in the criminal justice system. Outside of the United States, the terms prison and jail are used interchangeably to describe correctional settings.

HISTORICAL TRENDS IN INCARCERATION

Between 1972 and 2002, the number of adults in US prisons rose by 705%. This rapid increase in the incarceration rate reflects several social and political shifts that began in the 1970s. In 1971, US President Nixon declared a "War on Drugs." Criminalization of drug offenses was followed by four decades of stricter sentencing and release laws, longer sentences, and court precedents that allowed for more liberal police searches of individuals for contraband (e.g., "stop and frisk"). Concurrently, individuals with mental illness were transferred from permanent psychiatric facilities to community-based mental health programs, debatably resulting in "trans-institutionalization," or the incarceration of people with mental illness.[1] Notably, rising incarceration rates have not paralleled crime rates. Overall and serious crime rates have declined since 1991, yet incarceration rates increased in the United States until 2009, when many states instituted policies for early release and jail diversion options to nonviolent offenders[2] that have been shown to reduce costs and re-offense rates more effectively than locking people up.[3]

Similar patterns of criminalization of drug offenses, increased sentencing duration, urbanization, and growth in incarceration have been noted across the globe. Between 2008 and 2011, 78% of countries saw their prison population grow. The global incarceration rate is outpacing the population growth rate by 5–10%,[4] and this has significant social impacts on groups that are disproportionately affected by incarceration.

EPIDEMIOLOGY: WHO IS INCARCERATED?

An estimated 10.2 million individuals are held in correctional facilities worldwide, and of these, 2.24 million are detained in the United States. Thirty million people pass through a correctional facility each year with greater than one-third of these being in the United States alone. The United States has the highest prison population rate in the world, 716 per 100,000 people, significantly more than similarly developed countries in Western Europe, such as the United Kingdom (148) and France (98), and even more than Russia (475) and China (121). In more practical terms, in the United States, 1 in 100 adults are presently in jail or prison, and 1 in 45 are on parole, probation, or supervised release.[5]

Globally, most prisoners are young men. Although 95.5% of those in jail or prison are male, the population of women, ranging on average from 2% to 9% of the total incarcerated population, is increasing at a faster rate. Also, prisoners tend to be young. The average age of prisoners in Europe and the United States is in the early 30s. Of note, the number of older prisoners (older than 55 years) in the United States[6] doubled between 1999 and 2012. At the other end of the spectrum, juveniles (younger than 19 years) account for 5% of the prison population in developed countries.[7] Juvenile incarceration is the single greatest predictor of recidivating to prison as an adult.

Inmates have low educational attainment and frequently face unemployment and homelessness. In the United States, 68% have no high school degree, and 31–40% scored in the lowest level of literacy on the National Adult Literacy Survey. Prior to incarceration, 28% of US prisoners were unemployed compared with the national rate of 5%. Over half of US prisoners made less than $1000 per month prior to incarceration, and 11% were homeless during the year prior to incarceration. Incarceration is estimated to decrease lifetime earnings by 40%, largely due to an absence of educational and professional development while in prison.[8]

There are large racial disparities in incarceration rates. In the United States, 1 in 17 white men, 1 in 6 Latino men, and 1 in 3 African-American men will have been incarcerated in their lifetimes. Similarly in England and Wales, black people are seven times more likely to be searched by police, and five times more likely to be incarcerated, than white people. Criminal justice involvement is not only highly prevalent but also is more likely to affect racial and ethnic minorities, the poor, and the undereducated, magnifying socioeconomic and health disparities in these groups.

HEALTH CARE IN PRISONS: A PUBLIC HEALTH OPPORTUNITY

> Prior to going to prison, Mr. Clark went to the emergency department for most of his medical care. He was surprised by his diagnosis of hypertension in prison. He noted that the routine in prison facilitated his ability to take his medicines every day and keep his blood pressure under control.

RIGHT TO HEALTH CARE IN PRISONS

Following the atrocities that prisoners suffered during World War II, the United Nations adopted the Standard Minimum for the Treatment of Prisoners, which lays out basic legal and medical rights. In 1990, the United Nations recommended that prisoners "have access to health services available in the country." The US Supreme Court decision, Estelle v. Gamble (1976), in advance of the recommendation, already guaranteed a constitutional right to health care in prisons. These precedents have interesting implications for prisoner health care. First, incarcerated individuals may have guaranteed access to care in countries, including the United States, where there is no universal mandate for health care. Second, because these mandates require equivalence of care, prisoners, who often have greater medical needs than community members, may actually need greater health care than that provided. Prisons have long been thought of as unique settings for screening, treatment, and prevention of communicable diseases in "hard-to-reach" and high-risk populations.[9] Screening and treatment of prisoners for both communicable and noncommunicable diseases (NCDs) may have a positive effect not only on the health of the individuals but on the health of their families and communities as well, thereby constituting an investment in general public health.

HEALTH PROMOTION IN PRISONS

Providing universal and equivalent health care for prisoners is not just a human rights issue, but many scholars point out that it is also a matter of public health. The prevalence of many conditions is greater in prisoners than in the general population and other high-risk groups. Therefore, in jail settings, where the average length of stay is 48 hours, prompt screening and treatment of infectious diseases directly prevents transmission in communities. Prisons, on the other hand, where longer stays are the norm, offer opportunities for continuity of care, initiation of long-term therapeutic regimens, substance use and mental health treatment, and screening and lifestyle factor modification to prevent NCDs. Settings-based approaches that not only focus on medical care provision but also create an environment that fosters wellness, through opportunities for fitness, nutrition, and peer education, have been advocated and applied largely in the United Kingdom. The goal of these health promoting prisons is to improve "health resilience" of individuals with a history of incarceration by reducing health disparities and recidivism risk.[6] The success of these programs may be limited by the inherent differences between the roles of the health-care system, to promote health, and correctional system, to punish or promote security.

CHALLENGES TO HEALTH-CARE DELIVERY IN PRISONS

In addition to the ideological incongruence between the health care and correctional missions, there are many barriers to providing quality care to inmates. While organizations, such as the World Health Organization (WHO) and National Commission on Correctional Health Care, disseminate recommendations for health-care provision in prisons, no organizations are tasked with evaluation or enforcement, and as a result, these recommendations can go unimplemented.

At an institutional level, cost of care, access to medical specialists, distance to medical facilities, and sheer patient volume limit care delivery. In the United States, health care accounts for 20% of the overall prison budget, and this share is growing with an aging prison population.[6] These older prisoners have more complex medical needs that may require specialists at an outside hospital or clinic. The cost of transportation to and from these facilities, as well as providing security escorts, can also be substantial.[6] These issues are compounded by high incarceration rates, which contribute to patient volumes that overwhelm the capacity of medical staff and facilities and to long wait times for medical care.

At the individual level, short stays in jails and confidentiality concerns can thwart effective care provision. Many jail detainees are held for a few days until they can post bail. Thus, inmates who are screened and/or diagnosed may be released prior to treatment being initiated or completed. Confidentiality is difficult to achieve in correctional settings, and fear that other prisoners and correctional officers may find out about medical conditions may prompt a prisoner to refuse screening or treatment for known infectious or chronic conditions.

Several studies have corroborated that management of chronic conditions is improved in correctional facilities and mortality rates for African-American men due to chronic disease are lower in prison than in the community.[10,11] Researchers have posited that stable housing, adequate nutrition, guaranteed access to care, and decreased access to alcohol and illicit substances contribute to these

gains.[10] These studies suggest that enhanced access to care and the salutatory environment in prison have the potential to reduce health disparities.

- Patients are not often asked about a history of incarceration, despite the fact that it is extremely common to have been incarcerated or have a family member incarcerated and that it confers unique health risks.
- Prisoners' health needs are complex due to numerous socioeconomic and health disparities.
- Opportunities to address health issues of prisoners are often overlooked in prison and overlooking health issues of prisoners can have serious public health consequences.
- Incarceration poses health risks of its own that are overlooked if practitioners do not know about the prison or jail history.
- Jails and prisons have inconsistent and largely inadequate screening and treatment of illnesses common to inmates.
- Mental health and substance abuse issues that increase the likelihood of recidivism often are unaddressed.
- Provision of adequate health care to inmates is costly and complicated by the security mission of prisons.
- A criminal record imparts collateral consequences that harm a patient's successful reintegration to the community and undermine access to health-promoting resources.

Mr. Clark has a longstanding history of depression and heroin use disorder. Additionally, during his last 2 years in prison, he was diagnosed with hypertension, screened negative for HIV and tuberculosis (TB), and had a routine colonoscopy, notable for a benign polyp. He was told that he had Hepatitis C (HCV), but he could not recall his viral load.

HEALTH DISPARITIES IN INCARCERATED INDIVIDUALS

The health status of incarcerated individuals is complicated by the same risk factors that may have contributed to their being incarcerated in the first place—addiction, mental illness, poverty, low educational attainment, and racial and sexual discrimination. High rates of injection drug use (IDU) and risky sexual behaviors strongly predispose incarcerated individuals to HIV, HCV, and sexually transmitted infections (STIs). However, studies have demonstrated that incarceration is an independent risk factor for disease, suggesting that the correctional setting may directly promote disease.[12,13] Correctional settings also influence the risk of disease in more nuanced ways, through a process of social marginalization, disruption of social networks via "forced migration" in and out of prisons, and decreased choice in care and other health-promoting resources.

COMMUNICABLE DISEASES

HIV/AIDS

Globally, prisoners, especially female prisoners, are much more likely to be infected with HIV as compared with those without a history of incarceration.[14] Accessible, low-cost antiretroviral therapy (ART) in the community and prisons has decreased the burden and mortality associated with HIV in correctional settings.[15] In the United States, between 1992 and 2008, rates of HIV+ prisoners decreased from 2.5% to 1.5% and AIDS-associated mortality decreased from 34.2% to 4.6%.[7,16]

Despite the gains in HIV-associated outcomes, several key issues undermine the implementation of HIV care in correctional settings. Discharge practices for HIV care vary substantially by region and correctional setting in the United States.[17] Evidence suggests that even when inmates are released with prescriptions for ART, few actually fill these prescriptions in time to avoid treatment interruption.[18] Discontinuity in care likely contributes to high rates of resistance and poor viral suppression in individuals with a history of incarceration, and these outcomes are magnified by recidivism. In a Canadian study of HIV+ IDUs, the number of incarceration events predicted poor adherence to ARTs in a dose-dependent fashion.[19] Interventions to improve discharge planning and transitional care for inmates with HIV will be discussed at the end of this chapter.

Hepatitis B and C

Hepatitis B and C infections represent a growing epidemic in incarcerated populations. Chronic Hepatitis B virus (HBV) infection is 7.4, 4, and 50 times higher in prisoners in the United States, the Netherlands, and Brazil than in the overall populations.[20] In light of these marked disparities, the WHO and Centers for Disease Control and Prevention (CDC) recommend universal hepatitis B vaccination for unvaccinated individuals in prisons.

The burden of HCV infection is even greater, with a prevalence of 30–40% in prisoners worldwide. It is estimated that one in three individuals with chronic HCV in the United States pass through a correctional facility each year and that 12–35% of US inmates have chronic HCV. Although the CDC recommends opt-out screening (screening everyone, except those that decline) for HCV in prisoners born between 1945 and 1965, many experts, citing incarceration itself as a high risk, recommend universal opt-out screening as more efficient and potentially cost-effective.[21]

Two major limitations to initiating HCV treatment in prisoners are the cost of therapy and duration of incarceration. To initiate treatment, one study stipulated that inmates stay in prison for the duration of treatment (up to 15 months), defer parole, and accept transfer to a 24-hour nursing facility. Despite these additional criteria and the high rates of psychiatric and HIV comorbidity, 49% of prisoners met eligibility criteria, 61% completed treatment, and 47% of those who initiated treatment had a sustained virologic response.[22] HCV treatment initiation in prisons is complicated, yet feasible; expensive with the potential to be cost-effective; and has the potential to shrink the burden of HCV in incarcerated individuals.[21] Newer treatments for HCV could simplify the logistics for treatment and provide great health benefits but, at current prices, would overwhelm correctional budgets.[23]

Sexually Transmitted Infections

High-risk sexual behaviors, sexual victimization, poverty, and substance use likely influence STI risk in prisoners. Rates of chlamydia, gonorrhea, and syphilis are much greater in prisoners than in the community or other high-risk settings, although comparisons are difficult owing to the absence of universal screening in the general population. Globally, women and juveniles have higher rates of STIs, with estimates in incarcerated juveniles of 2–10 times higher than peers in the community.[7] The CDC recommends universal screening for syphilis, gonorrhea, and chlamydia in jails and prisons, yet these practices have not been universally adopted. In areas where screening and treatment have been adopted in local jail populations, prevalence of STIs in the surrounding community has been shown to decline, revealing the interconnections between jail populations and their surrounding communities and offering one perspective of prison health care as a public health opportunity.[24]

Tuberculosis

Common risk factors for TB—homelessness, poor nutrition, IDU, HIV, and poor access to health care—track those of incarceration and contribute to rates of TB in prisoners that are 18 and 33 times greater than in the populations of high and low-to-middle income countries, respectively.[25] Coinfection with HIV, estimated at 13.2% in prisons, has contributed to an international resurgence in TB rates.[26] A study of incarceration growth and rising TB incidence in Eastern Europe and Central Asia demonstrated that mass incarceration magnifies community TB transmission.[27] Prison outbreaks of multidrug resistant (MDR) TB have been reported, and in Estonia, up to 50% of TB cases are MDR. TB is not only highly prevalent in prisons, but it is also spread readily in prisons due to overcrowding and poor ventilation. Globally, screening and treatment of TB in prisons is a priority. The WHO recommends routine screening chest x-rays at prison entry, with follow-up sputum microscopy and culture and resistance testing to contain TB.

Noncommunicable Diseases

The disproportionate prevalence of infectious diseases, substance use disorders (SUDs), and psychiatric disorders have overshadowed the assessment of the NCD burden in prisoners. However, the aging of this population and global rise of obesity-related illness have shifted focus to NCDs. As the risk factors for these diseases are modifiable, experts highlight how the prisons can support smoking cessation and improved diets and exercise. Poor diets particularly affect female inmates who are more likely to be overweight and obese than non-incarcerated women.[28] Additionally, US inmates are more likely to have hypertension, asthma, and arthritis than non-incarcerated adults.[29] Given this increased risk for many conditions, it is not surprising that 65% of older inmates experience at least one nonpsychiatric chronic disease.[30]

Cancer

Rates of lung, oropharyngeal, and cervical cancers are overrepresented in prisoners. Hepatocellular carcinoma is seven times more common in the incarcerated as compared with the US male population.[31] Higher rates of these cancers likely reflect higher rates of smoking, alcohol use, HCV, and HBV in prisoners.[32] and cancer treatment raises financial and ethical considerations for correctional institutions, especially at the end of life. Therefore, prisons may opt instead for "compassionate release," or early release, of seriously ill prisoners to the community.[33] Alternatives to early release, such as prison hospices and palliative care provider in-reach, have been successfully implemented.[34,35]

Mental Illness

Mental illness is a dominant condition in prisons. A worldwide, systematic review estimated that 65% of prisoners have a mental health disorder with rates of depression at 10–14%, personality disorders from 40% to 70%, and psychotic disorders at 4%.[36] Additionally, in prisoners with mental illness, 20–40% also suffer from SUDs. Notably, 95% of juvenile detainees have a psychiatric disorder, and they are 10 times more likely to have a psychotic disorder than non-incarcerated peers.[37]

Inmates with mental illness, when compared with inmates without mental illness, are more likely to have a longer criminal justice history, serve longer sentences, and have higher rates of re-offending. These prisoners also have high rates of homelessness—double those of persons who are not mentally ill—as well as high rates

of unemployment, alcohol and drug abuse, and a history of physical and sexual abuse prior to incarceration. Moreover, mental illness is not just a problem associated with crime; it is a major cause of morbidity and mortality among incarcerated individuals. Fifty percent of prison deaths worldwide are attributed to suicide. Suicide rates in male prisoners are two to eight times higher than that in general population, and self-injurious behaviors are common with one in four women reporting self-injurious behaviors while incarcerated.[38]

However, mental illness often goes unrecognized and untreated in correctional settings. In the United States, one-third of inmates with schizophrenia did not receive pharmacologic treatment for their disorder while in prisons or jail.[29] Conversely, some report that antipsychotics are overused or used inappropriately. Nonpharmacologic management for psychiatric disorders is less common. While 73% of state prisons in the United States distribute psychotropic medications, fewer conduct routine psychiatric assessments, provide mental health counseling, or provide linkages to community mental health care.[39] Mental illness in prisoners is prevalent, but with appropriate treatment may be a modifiable risk factor for incarceration.

Substance Use Disorders

Criminalization of drug offenses has contributed to global mass incarceration. With the advent of policies such as "mandatory sentencing" and "three strikes laws" in the United States, nonviolent drug offenders are sent to prison more readily and sentenced for longer durations. Consequently, the estimated prevalence of SUDs in prisoners is 2 to 10 times greater than the community prevalence. Importantly, SUDs are the most significant risk factor for mortality on release from prison and are highly correlated with recidivism.

Therefore, the rationale for treating SUDs in incarcerated individuals is clear. The National Institute of Drug Abuse suggests that for every $1 spent on drug treatment, $12 is saved in decreases to drug-associated crimes and incarceration. However, professional treatment for SUD in US prisoners is rare at around 11%. Twenty-two percent of inmates participate in peer-led counseling programs and suggests that need for treatment of SUD is higher than formal treatment offered in prisons. Alternatives to incarceration (e.g., drug courts) for drug offenses may decrease re-arrests, future convictions for drug-related offenses, and costs associated with incarceration.[40] While SUDs have contributed to the growing rates of incarceration, recent evidence has shown that treatment for these conditions both in and out of the correctional setting may decrease the costs and social impacts of substance use, in addition to providing durable treatment for the patient.

INCARCERATION AS A RISK FACTOR

CORRECTIONAL SETTINGS MAKE PEOPLE MORE VULNERABLE TO ILLNESS

Risky Sexual Behaviors or Rape

Sexual activity is prohibited in prisons, yet consensual and nonconsensual sexual acts are common and can contribute to the spread of communicable diseases. In the United States, 3–4% of inmates reported incidents of sexual victimization by other inmates or correctional staff. These data may be underestimated as they are based on inmate self-report.[41] Rates of sexual victimization were three times greater in LGBT and women inmates and 2.5 times greater in mentally ill inmates. The WHO recommends condom provision and post-exposure prophylaxis as part of a harm reduction strategy in prisons.

Blood-Borne Infections: IDU and Tattooing in Prison

Use of shared needles for drug use and tattooing are a documented source of blood-borne infections in prisons. IDU is common in some prisons, and studies in the United States estimated that 14–25% of inmates have injected drugs in prison.[42] IDU in prisons increases disease transmission—individuals who report IDU in prison are eight times more likely to acquire HCV in prisons than those who do not engage in IDU.[20] Tattooing also is practiced widely in prisons and usually is done without sterilized needles. Given these risks, the WHO recommends that prisons offer needle exchange programs and post-exposure prophylaxis. Needle exchange programs have been successfully implemented in prisons in 77 countries worldwide.

Violence and Post-Incarceration Syndrome

Exposure to violence and trauma is common among prisoners. In Australia, 34% of male and 24% of female prisoners had been physically assaulted while incarcerated. Rates of juvenile violence are even higher than that of adults. Exposure to violence can have long-term effects on inmates that persist even after release, leading experts to identify and categorize a unique cluster of symptoms similar to post traumatic stress disorder (PTSD), termed post-incarceration syndrome (PICS). Although not systematically studied, PICS is theorized to affect inmates' ability to transition successfully back to the community, make decisions on release, and form relationships in the community.[43]

Solitary Confinement and Mental Health

Solitary confinement is used to discipline inmates by placing them in a single-person cell, restricting interactions with other inmates and correctional staff, and allowing only 1 hour out of the cell each day. Many experts suggest that inmates with preexisting mental illness are

particularly susceptible to the pernicious effects of this type of isolation and sensory deprivation. Several studies have shown that solitary confinement increases the rate of suicide and self-injurious behavior in inmates.[38] Consequently, the American Psychiatric Association has deemed that "prolonged segregation of adult inmates with serious mental illness, with rare exceptions, should be avoided due to the potential for harm to such inmates."

> Mr. Clark was released from prison with a Medicaid card, a flyer for a local primary care clinic, and 4 weeks of medications. Unfortunately, he lost his medications when he did not make it to homeless shelter in time for the night. Instead, he went to emergency department to get medication refills. He was feeling "very low" and relapsed on heroin earlier that week.

RELEASE FROM CORRECTIONAL SETTINGS MAKES PEOPLE MORE VULNERABLE

Morbidity and Mortality

Unlike inside jails and prison, there are no government guarantees for health care in the United States once inmates are released. This poses significant issues given that 80% of US prisoners have a chronic medical, substance use, or behavioral health condition at entry, and 40% of prisoners are diagnosed with new conditions while incarcerated.[44] The mortality rates for recently released prisoners are greater than 12 times that of the general population in the first 2 weeks post release, with drug overdose, cardiovascular disease, homicide, and suicide, as the leading causes of death.[45] Across the globe, the majority of deaths in the immediate period following release are drug overdose related,[46] in the setting of reduced tolerance. Suicide rates are also high. In recently released UK prisoners, suicide rates were 8-fold (men) and 39-fold (women) greater in the first year postrelease as compared with the general population.[47] Increased risk of mortality peaks at 2 weeks, but some studies indicate that the mortality risk can persist for years postrelease.

Health-Care Access and Utilization

Efforts to engage formerly incarcerated patients into follow-up care, especially primary care, have proven difficult. Only about 15–25% of formerly incarcerated patients see a physician outside of the emergency department in the first 12 months postrelease.[48] Recent release or arrest is associated with increased use of the emergency department and risk of hospitalization. Moreover, despite making up only 4.2% of the US population, recently released individuals account for 7.2% of hospital expenditures and 8.5% of emergency department expenditures.[49]

Medication Continuity

Upon release, formerly incarcerated patients are lucky to be given even a limited supply of medication and they often must learn to fill medication prescriptions or self-administer their medications for the first time. Low rates of medication continuation is the norm, pointing to barriers such as patient education and coordination between correctional and community health-care providers.[48]

Collateral Consequences

The ability of former inmates to care for their medical conditions is further compromised by poor access to health insurance and other public entitlements. Many states terminate Medicaid benefits upon incarceration. When individuals are released without Medicaid, they are unable to refill medications or seek medical treatment. Some states prohibit access to food stamps for individuals convicted of drug crimes. Food insecurity not only interferes with the management of chronic conditions such as obesity, cardiovascular disease, and diabetes, but, among recently released patients, it has been directly tied to engagement in HIV risk behaviors.[50]

Unfortunately, discharge planning for medical needs may also ignore other significant social barriers to reentry, such as housing and employment. A large proportion of formerly incarcerated individuals are insecurely housed, leading to high rates of homelessness upon release. Federal laws may also prevent individuals with specific conviction records from residing in public housing with their families or on their own. Concurrently, discrimination against former inmates in employment settings has been well documented, and in most states, individuals are still required to "check the box" when applying for a job. Chronic unemployment bars former inmates from successfully reentering the community and may contribute to high rates of recidivism.[51]

> Mr. Clark's substance use disorder and homelessness contributed to his imprisonment. After reviewing his medical history, refilling his medications, and referring him to a mental health counselor, he asks about ways to reduce drug cravings. He is referred to opioid maintenance therapy. With Mr. Clark's permission, a letter is written to his parole officer to describe the indications for this medication. At the end of his visit, a social worker reviews Mr. Clark's options for housing.

MEDICAL MANAGEMENT OF FORMERLY INCARCERATED PATIENTS

INTEGRATING TRANSITIONAL CARE

Physicians and nurses are responsible for the direct provision of medical care to patients returning home from prison. However, it is important for these providers to

Box 27-2. Coordinated Discharge Planning

Discharge planners: Department of Corrections (DOC) employees who meet with individuals prior to release to carry out needs assessments and develop tailored reentry plans.

- Key roles: Medication provision and follow-up appointments, continuity between correctional facilities and community services providers, reenrollment in public benefits

Parole and probation officers: Criminal justice personnel who oversee individual's compliance with the terms of these sentences, including abstinence from drug use, participation in substance use treatment, or search for employment.

- Key roles: Parole and probation officers may play a crucial role in referring individuals to care; however, given the supervisory nature of these officers, health providers should emphasize their separate role from the criminal justice system.

Care management:

- Social workers assist individuals to obtain health insurance and care referrals, reconnecting with their families, and referring them to social services.
- Substance abuse counselors may work closely with other health-care professionals to address recently released individuals' risks and personal "triggers"—for substance use.
- Community health workers specialize in "bridging" the gap between underserved populations and the health-care system, and are often members of the very neighborhoods and communities that they serve.

Reentry councils: Local reentry councils coordinate efforts between the DOC, city officials, and other social service agencies to best serve the needs of recently released individuals.

- Potential stakeholders: Local government, district attorney's office, police department, parole and probation, department of social services, nongovernment organizations.

understand the roles that individuals and community organizations play in coordinating successful reentry (Box 27-2). Without these community organizations, engaging patients in medical care may be futile, and treatment may be undermined without appropriate attention to the social determinants of health.

OBTAINING AN INCARCERATION HISTORY

Given the stigma of incarceration, it may be difficult to introduce the topic of incarceration. This history has important implications for a patient's and their families' well-being. Making clear that avoidance of reimprisonment and the health consequences of prison are your concerns as a provider may make asking questions about this topic less difficult. In communities most affected by incarceration, histories of incarceration may be volunteered and screening, in the context of a trusting relationship, may be worthwhile by asking patients: Have you or any of your family members been incarcerated?

By forming a therapeutic alliance and allowing the patient to feel safe in the clinical setting, a provider may obtain an incarceration history in order to discuss discrete health concerns, including prevention of future incarceration. It is usually not beneficial to either the patient or provider to address reasons for incarceration or criminal history. However, the provider should elicit patients' priorities in coming home and collaboratively offer strategies to reduce re-incarceration, including treatment of SUDs and mental illness. Providers should avoid using medications that may trigger a parole violation (e.g., opiates). If these medications are deemed crucial, a letter to the probation officer may protect a former inmate from problems with the system. Periodically reassess patients' risks for re-incarceration, especially if they missed several appointments, did not refill their psychiatric medication, or have recently become homeless.

Primary care providers may obtain more thorough incarceration histories from patients who were recently released (see "Core Competency"). In some cases, clinicians will obtain medical records from discharge planners to assess a patient's treatment, new diagnoses, and routine health screening inside prison.

HOW TO REDUCE RISKS ASSOCIATED WITH INCARCERATION

INDIVIDUAL PROVIDER ADVOCACY

Providers can help decrease the risk of incarceration and mitigate the effects of incarceration on patients, families, and communities. Advocacy for positive change in the health of patients often begins with one individual patient. Addressing the broad-reaching influences that incarceration has on employment, political participation, housing, and the custody of children is important. The direct and collateral consequences of incarceration can compromise an individuals' ability to meet even basic needs on release—housing, food, and a source of income through employment. Therefore, addressing their pressing medical needs may not be the first priority for individuals returning home.

Providers advocate for patients returning home in different ways than for traditional patients (see Chapter 8). First, providers may collaborate with social workers and community health workers to actively engage patients in care. We encourage providers to think critically about how to tailor these outreach interventions by reviewing studies about health and racial disparities in persons with a

history of incarceration and evidence-based interventions, such as the ones presented in the next section. Second, providers may participate in political advocacy for patients with a history of incarceration. On a daily basis, providers bear witness to the ways in which criminal justice policy undermines the lives and health of their patients, families, and communities. Connecting with a city's reentry council to see what types of services are offered may also reduce the impact of incarceration. For example, patients with a history of incarceration face job discrimination, and reentry councils often aggregate lists of employers who will hire individuals with a criminal record; providing this list to patients and clinic social workers may lead to improvements in the health of this population. For information on organizational advocacy, see the list of organizations provided at the end of the chapter.

EVIDENCE-BASED APPROACHES TO REDUCE HEALTH IMPACTS OF INCARCERATION

ENHANCELINK: ENGAGING HIV+ INMATES IN CARE ON RELEASE

EnhanceLink is a 10-site study that evaluates HIV care engagement of individuals released from urban jails in the United States.[52] Each site offers unique programmatic elements and incorporates case management, adherence support, and treatment of SUDs and mental illness.[53] Upon discharge, 61% of releases enrolled in EnhanceLink had a follow-up appointment with an HIV Primary Care Provider (PCP), 38% had an appointment with a substance use counselor, and 23% with a mental health counselor. Among the two-thirds of individuals who followed up in care post-release, the strongest patient-level predictors of engagement were being male and having an HIV provider prior to incarceration.[52] Women were not only less likely to follow up in care, but they were also three times less likely than men to have viral load suppression 6 months post-release.[54]

The EnhanceLink interventions drew individuals into HIV care regardless of homelessness, drug use, or medical comorbidity.[55] EnhanceLink's findings suggest that by fostering transitional partnerships between the correctional and community setting, health providers may more effectively engage in HIV+ inmates on release. These partnerships offer the dual benefit of mitigating discontinuities in care on reentry and leveraging the potential of correctional settings to serve as a bridge to care for HIV+ individuals.

Transitions Clinic Network: Culturally Competent Primary Care for Patients with a History of Incarceration

The Transitions Clinic Network is a network of 13 community-based clinics across the United States that provide integrated primary care to individuals returning home from prison with chronic medical conditions. These programs operate within preexisting community health centers; train primary care providers to care for and address the complex medical and social needs of patients with a history of incarceration; and employ community health workers with histories of incarceration to provide social service, health-care navigation, and chronic disease management support.[56] A randomized control trial demonstrated that when compared with expedited care in community-based clinics, the Transitions Clinic significantly reduced emergency department utilization.[44] Transitions Clinic offers a model to engage individuals in primary care after release, smooth transitions in care during reentry, and tailor care to meet unique needs of patients following release from prison.

Opioid Maintenance Therapy: Reducing Risk in and out of Correctional Settings

Opioid maintenance therapy reduces drug use and sexual risk behaviors in other underserved populations, and similar findings have been consistently found among incarcerated individuals. A systematic review demonstrated that opioid maintenance therapy initiated in prison reduced heroin injecting and needle sharing in the correctional setting and increased opioid maintenance therapy entry and retention postrelease.[57] A single study conducted in Australia followed up heroin users randomly assigned to receive methadone maintenance therapy in prison. Investigators collected outcomes on these individuals 4 years postrelease. Individuals who received methadone maintenance therapy for 8 months or more were 70% less likely to be re-incarcerated as compared with those who did not receive methadone maintenance therapy. Individuals who received 5 months or less of methadone maintenance therapy were significantly more likely to acquire HCV. Methadone maintenance therapy reduced mortality regardless of duration of therapy. These results suggest that providers who are able to treat and retain patients on methadone maintenance therapy may not only improve risk behaviors and health outcomes but also may reduce recidivism.[58]

CONCLUSION

One in 35 individuals in the United States will have been incarcerated during their lifetimes, and this event has long-lasting consequences on the health of these individuals, their families, and communities. Individuals who are incarcerated are not only more likely to suffer from many medical conditions but also are made more vulnerable by the peculiar conditions of correctional settings and on transition to the community. A history of incarceration carries social stigma and collateral consequences that are

not easily mitigated, and providers should be cognizant of the myriad ways that incarceration impacts health of patients and their families. Recidivism is real concern for patients returning home from prison, and providers should be attuned to their role in preventing cycles of future incarceration and advocating for criminal justice reform. The number of older prisoners entering and aging in prison continues to grow and will place additional burdens on prison administration, as they have differentiated social, custodial, and health-care needs than prisoners who are younger and relatively healthier.[59]

- Risks factors for incarceration, including poverty, addiction, mental illness, homelessness, and educational status, are often made worse by incarceration.
- Prisoners have higher burdens of mental illness, infectious diseases, and SUD, and present to care later in the course of chronic disease.
- Prison health care is limited by the resource constraints in prisons, lack of confidentiality, and focus on security that are inherent in the corrections setting.
- On release from prison, individuals are at risk for mortality, medication discontinuity, and collateral consequences.
- Community providers can play an important role in helping their patients' transition from prison to the community and reducing rates of incarceration and recidivism.

Clinical Visit in Patients Returning Home

Setting the scene: Establish a comfortable rapport with the patient. Build trust by broaching sensitive topics about incarceration and reentry respectfully and without judgment. Prefacing your inquiry as an effort to mitigate the harms of incarceration and help prevent future re-incarceration may be helpful.

Prison can be very harmful to a patient's health. I want both to make sure we take care of any health problems that came up for you because you were incarcerated and see if there are ways that we can help prevent you ever going back to prison.

Incarceration history: May I ask you some questions about the time you spent in prison?

- When were you released from prison? How long were you incarcerated?
- Are you currently on probation or parole? When does this term end?
- Were you diagnosed with any medical conditions in prison? Were you taking medications for these conditions in prison? Were you released with any medications?

Reentry history: My patients often find that it is difficult to take care of their health on top of all of the other demands of returning home from prison.

- How is this process going for you? What have you found challenging coming home?
- How has this impacted your health and your ability to manage your medical conditions?

History and physical exam: Pay particular attention to and screen for the following issues:

- Medical conditions diagnosed in prison
- Adherence and access to medications
- Current or past substance use; cravings; history of substance use treatment
- Depression and suicidality; PTSD and exposure to violence, trauma, or sexual abuse
- Housing concerns, food security, employment, access to medical insurance
- Lab screening: TB, HCV, HBV, syphilis, HIV, and other STIs

Action plan: Thank you for sharing with me. I would like to discuss your goals in managing your health and staying out of prison. It is my hope that by addressing your health conditions and other concerns, we can work together to keep you out of prison.

- Provide education about medical conditions and medication; refill medications
- Refer patient to specialists for medical, mental health, and substance use issues; social worker for assistance with Medicaid, public benefits, and employment; legal counsel for obliteration of criminal record, pending criminal charges, and child custody issues

DISCUSSION QUESTIONS

1. Why are prisoners considered a vulnerable population?
2. What are the ways in which prison confers vulnerability both in prison and on release?
3. What social and medical barriers do individuals returning home from prison face? How does this impact health? Risk of recidivism?
4. What can providers do to improve transitions of care for individuals returning home from prison? What actions can they take to reduce patients' risk of recidivism?

RESOURCES

The Pew Charitable Trusts: http://www.pewtrusts.org/en/topics/public-safety.

Prison Policy Initiative: http://www.prisonpolicy.org/.

The Sentencing Project: http://www.sentencingproject.org/
Urban Institute: http://www.urban.org/Justice/index.cfm.

Vera Institute of Justice: http://www.vera.org/.

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Adam Gopnik's "Caging of America" in the New Yorker: http://www.newyorker.com/magazine/2012/01/30/the-caging-of-america.

Atul Gawande's "Hellhole" in the New Yorker: http://www.newyorker.com/magazine/2009/03/30/hellhole.

FRONTLINE's documentary "Locked up in America": http://www.pbs.org/wgbh/frontline/investigation/locked-up-in-america/.

Eugene Jarecki's documentary The House I Live In: http://www.thehouseilivein.org/.

TedTalks by Angela Patton and Shaka Senghor: https://www.ted.com/talks/shaka_senghor_why_your_worst_deeds_don_t_define_you.

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Chapter 28

Care of the Homeless Patient

Margot Kushel, MD and Sharad Jain, MD

Objective

- Define homelessness and identify risks for homelessness.
- Describe the epidemiology of homelessness, including morbidity and mortality.
- Review medical conditions common among the homeless.
- Identify challenges to providing care to homeless patients.
- Identify interventions to improve care, both at the provider and system levels.

Mr. Jones rarely comes to clinic appointments and often leaves before being seen, as he is afraid of not getting a shelter bed in time. He has been homeless for years. He has schizophrenia, hypertension, and has difficulty controlling his diabetes.

INTRODUCTION

Being homeless has a profound effect on health. Homeless patients have higher rates of chronic illness, morbidity, and mortality than patients who have stable housing.[1-7] Lacking insurance and transportation, their access to care is limited. Obtaining food and shelter are higher priorities for the homeless person than seeking health care.[8,9] Homeless patients present for medical attention later in the course of their illness.[10,11] Comorbid conditions such as mental illness and substance use can complicate adherence to treatment plans. Furthermore, providers often do not incorporate the challenges faced by homeless patients into management plans. This chapter explores the relevance of homelessness to health and health care and presents strategies to improve the care that homeless patients receive.

EPIDEMIOLOGY

In the United States in 2013, a total of 610,042 individuals were homeless on a single night and an estimated 2.5–3 million people experienced homelessness over the course of the year.[12] Over one-third of individuals experiencing homelessness are persons in families and one-fourth of all Americans who are homeless are children.[13] The median age of the homeless population is rising at a rate faster than that of the general population; the median age of homeless adults is now approximately 50 years.[14] This rise in the age of this population is thought to be attributable to a cohort effect: individuals born in the second half of the baby boom (1954–1965) have had an elevated risk of homelessness throughout their lives.[15] There is concern for another cohort effect, among those born in the 1990s.[16]

DEFINITION AND PATTERN OF HOMELESSNESS

The most commonly accepted definition of homelessness in the United States is from the Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH) Act of 2009.[17] The HEARTH Act updates the original

Federal definition, the McKinney Act of 1987.[18] The HEARTH Act defines a homeless individual as:

> An individual or family with a primary nighttime residence that is a public or private place not designed for or ordinarily used as a regular sleeping accommodation … living in a supervised publicly or privately operated shelter designated to provide temporary living arrangements; … individual who is exiting an institution where he or she resided for 90 days or less and who resided in an emergency shelter or place not meant for human habitation immediately before entering that institution.
>
> The HEARTH Act also includes individuals or families who will imminently lose their primary nighttime residence within 14 days and lacks resources or support to obtain permanent housing and those who are fleeing or attempting to flee interpersonal violence. It has a more expansive definition for homelessness for unaccompanied youth younger than 25 years or homeless families that includes those with severe residential instability and chronic disabilities or barriers to employment.

The chronically homeless person is defined by the Department of Housing and Urban Development as someone who has been homeless for at least 1 year or has had four episodes in a 3-year period and who has a chronic, disabling condition. Chronically homeless persons face multiple barriers to finding stable housing and employment. Although approximately 20% of people who experience an episode of homelessness are chronically homeless, approximately 50% of persons who are homeless at any point could be considered chronically homeless.[19] Chronically homeless individuals are more likely to be single men and have substance use and mental health problems. The intermittently homeless person is someone who has had multiple, short, self-limited episodes of homelessness. Most have spent time living with friends or family prior to losing their housing. Intermittently homeless people regain housing, but tend to be precariously housed; thus, they are at high risk of becoming homeless again. Typically, intermittently homeless persons have low income, low educational attainment, and may be escaping violent situations within their own homes. The prototypical intermittently homeless person is that of a member of a female-headed household that is struggling financially to get by.

The in-crisis homeless person is someone who has had one episode of homelessness brought about by a major crisis: an economic, health-related, or natural disaster (fire, earthquake). In general, those with crisis homelessness regain their housing and do not lose it again.

Unaccompanied youth, as opposed to homeless children living in families, are adolescents or young adults (up to 25 years old), living on their own without parents. These youth have often fled abusive situations or family disapproval caused by conflicts over their sexual identity. This population is marked by high rates of substance use, survival sex (exchanging sex for money, drugs, or housing), suicide, and transience, with high rates of movement between different cities. Another group of unaccompanied youth is those who have aged out of the child welfare system. Every year, 30,000 youth aged 16 and older age out of the system. Studies have shown that over a third of these youth experience homelessness by the age of 26.[20] A significant number of young women who do so are pregnant or parenting.

Although many of the necessary adjustments in providing health care are similar across the patterns of homelessness, each group presents unique needs and challenges.

HOMELESSNESS AS A MEDICAL PROBLEM

Many people, health-care providers included, do not consider homelessness a medical problem. Reviewing the complex causes and risks of homelessness, however, helps providers understand ways to intervene to prevent homelessness, mitigate its risks, and address medical issues. As homelessness worsens health, understanding the challenges faced by homeless individuals is essential to providing effective medical care.

CAUSES AND RISK FACTORS FOR HOMELESSNESS

The causes of homelessness are disputed. Some emphasize personal vulnerabilities (e.g., mental illness, substance abuse), and others cite systemic and structural problems (e.g., poverty, lack of affordable housing), as the root causes.[13] Homelessness can be conceptualized as resulting from a complex interaction of protective and risk factors occurring in the context of poverty and little access to housing (Table 28-1). While the primary risk factor for homelessness is poverty, health factors, including chronic illnesses and mental health and substance use problems, make individuals more vulnerable to homelessness. Intervening to mitigate the risks and bolster the protective factors may have a profound effect on health.

Personal Vulnerabilities

Poverty is the most essential personal and social vulnerability leading to homelessness, but it is not the sole determinant. Other personal vulnerabilities include childhood and adult victimization, and "out of home" experiences as a child (e.g., involvement in the foster care system, being homeless as a child, being in the juvenile justice system,

Table 28-1. Factors Influencing Homelessness

Protective Factors for Homelessness
- Financial resources
- Housing subsidy
- Social support
- Health
- Good housing and job availability
- Good employment history

Risk Factors for Homelessness
- Mental illness
- Chronic illness
- Partner violence
- Substance use
- Pregnancy
- Dependent children
- Poverty
- Lack of affordable housing
- Unstable employment history
- Unstable housing
- Poor social support
- History of homelessness
- History of incarceration
- Little availability of public assistance

being a runaway or "throwaway" child).[21,22] Many persons leaving state or federal prisons become homeless at discharge.

Structural Factors

Important structural factors include the availability of jobs that pay enough to allow people to maintain housing (and meet other basic needs) and the presence of affordable housing for low-income individuals. Social programs can be part of the "safety net" that prevents people from becoming homeless. Programs such as social insurance (Temporary Assistance to Needy Families, Social Security Disability Income, and county general assistance and unemployment insurance), rent subsidies (Section 8 vouchers), temporary housing, medical care, psychiatric care, and substance use treatment to low-income individuals can mitigate the effects of forces precipitating homelessness.

In an environment with limited low-cost housing and employment opportunities and an inadequate safety net, those lacking personal resources may become homeless; as the safety net erodes and the economy worsens, those with less vulnerability also may find themselves to be homeless.

HEALTH STATUS OF HOMELESS POPULATIONS

Homelessness is a concern for medical providers because not only can it be precipitated by medical problems, but also it puts people at risk for illness. Homeless people often are homeless because they are ill and ill because they are homeless.

Homeless persons have high rates of morbidity and mortality. More than one-third of all homeless persons report their health as fair or poor. In comparison, only approximately 11% of the population at large and slightly less than one-fourth of those individuals who live in poverty feel this way about their health.[10,23]

Homeless people have high rates of both acute and chronic illness. Homeless patients are more likely to contract communicable diseases such as tuberculosis,[24] and have higher rates of human immunodeficiency virus (HIV) infection and viral hepatitis because of the increased likelihood of unprotected sex and injection drug use.[25] Foot problems from walking in ill-fitting shoes, swollen legs, and poor dentition are other common problems. Rates of chronic illness are higher than in non-homeless cohorts, and can be challenging to manage, given limited access to health services, competing priorities, and barriers to disease management.

Homelessness puts women and children at particular risk for poor health.[26] Many women become homeless during pregnancy. Homelessness, in turn, puts them at risk for complicated pregnancies. Homeless women are also more likely to experience difficulty obtaining and using contraception, have multiple sexual partners, and have more unintended pregnancies, and are at high risk for physical and sexual assault.[21,27] Homeless children also have poor health. They suffer from more infectious diseases such as respiratory tract infections and diarrhea and have more nutritional disorders, asthma, and developmental delay than children with homes.[26]

Homeless individuals have high rates of smoking; approximately three-fourths of homeless adults are smokers.[28] While smoking rates have decreased in the general population, rates have not decreased in homeless populations. Smoking-related illnesses, including chronic obstructive pulmonary disease and cancer, are major threats to the health of homeless individuals.

Homeless individuals age 50 and older have rates of geriatric conditions, such as cognitive and functional impairment, similar to those over 20 years and older.[29] While health-care providers focusing on homeless adults have focused, traditionally, on acute and communicable diseases, the aging of the homeless population has increased the need to manage multiple chronic medical conditions, such as diabetes, hypertension, coronary artery disease, and chronic obstructive pulmonary disease which are often undiagnosed or inadequately treated in this population.

Rates of mental illness have varied widely among the homeless but are consistently higher than the general population. A nationally representative study of homeless individuals found that 57% of currently homeless individuals had a mental health problem in their lifetime and 39% currently suffer with a mental illness.[22] The relative

prevalence of different types of psychiatric impairments mirrors that in the general population, with depression, bipolar affective disorder, schizophrenia, posttraumatic stress disorder, and personality disorders being the most common.[30] Severe mental illness is more common among the chronically homeless population than other homeless populations, although rates are elevated throughout the homeless population.

In addition, homeless people have a high rate of substance use, which can complicate the medical care that they receive. Thirty-eight percent of currently homeless clients in a national survey were found to have a current alcohol problem, and 62% had an alcohol problem in their lifetime.[22] Approximately 25% of currently homeless persons have a problem with drug use, and 60% have a lifetime history of a drug use disorder.[22] Sixty-six percent of currently homeless persons have at least one mental health, alcohol, or drug problem; 86% have had at least one of the three problems in their lifetimes. Many have at least two of the three problems simultaneously. Thirty percent of homeless clients have a lifetime history of mental health and alcohol and drug problems.[22]

Homeless people have higher rates of inpatient hospitalizations than housed persons, likely because of delayed access to care and lower admission thresholds. Complying with both outpatient and discharge treatment plans may be more difficult, particularly if providers do not consider housing status when developing treatment plans.

Studies in the United States and Canada have shown that homeless persons have mortality rates approximately three to four times that of housed, age-matched controls, with a median age of death from 40 to 47 years old.[1,2,4,7,31-33]

HOMELESSNESS AND THE HEALTH-CARE SYSTEM

Homeless persons are cared for both within the mainstream health-care system and within a specialized system of care developed and funded to care for the homeless population (the federally financed Health Care for the Homeless system). While in the mainstream system, because of their poverty and lack of health insurance, homeless people are more likely to be cared for within the "safety-net" system of community clinics, public hospitals, and Veteran Affairs hospitals, than the private health-care system.[34]

Historically, fewer than half of homeless people are insured, and almost all of these have publicly funded insurance, such as Medicaid, Medicare, and veterans' insurance. Their access to ambulatory health care has been poor, and they tended to receive health care through emergency department and inpatient hospitalizations.[8] In addition to insurance issues and the competing priorities of food and shelter, other barriers to health care include poverty, low health-care literacy, and distrust of the medical establishment. However, with the passage of the Affordable Care Act, many homeless individuals are now eligible for Medicaid based on their low income, thereby improving their access to ambulatory care and preventive services.

The health-care system itself is a barrier,[35] and having a regular provider who can build a relationship with the patient, and help her or him navigate the system is of utmost importance. Despite the high prevalence of mental illness and substance use, for example, homeless patients often have difficulty accessing psychiatric care or substance use treatment. One study found that only 20% of those with mental health or substance use problems were receiving any treatment for these problems.[36]

STRATEGIES TO ADDRESS HOMELESSNESS AND ITS PROBLEMS

> Ms. Smith presents 1 hour late for her appointment at her community health center. Her two school-aged children are with her. She explains that since her appointment 6 months ago, she has been evicted from her apartment. She is living at her cousin's; there are now 10 people living in a two-bedroom apartment. She has run out of her asthma medicine; in the interview, she starts to cry and states that she cannot sleep at night, has no appetite, and feels hopeless. Her asthma, previously well controlled, is now flaring.

Homelessness and health care are recognized to be intertwined. In addition to the human costs of homelessness, the high costs of potentially avoidable acute health care have helped motivate solutions to end homelessness. This connection is reflected in the United States' Federal Strategic Plan to Prevent and End Homelessness,[14] which recognizes the roles of health-care providers in ending homelessness.

"CLOSING THE FRONT DOOR:" PREVENTION OF HOMELESSNESS

Prevention is the ideal way to address homelessness. Strategies to prevent homelessness depend on which population is being addressed. For those with "crisis" homelessness, who generally have less personal vulnerability and more resources to draw on, efforts can be made to prevent eviction and stop the cycle of homelessness early. Community services provide legal support for tenants facing eviction, emergency financial assistance to cover back rent or utility bills, or case management to assist with applying for government benefits. Health-care providers can play a key role in identifying individuals at risk of becoming homeless and partnering with social and legal

services to prevent homelessness. Helping Ms. Smith to access these resources and advocating for her could have a more profound effect on her health and that of her children than prescribing more asthma medications.

To prevent chronic homelessness, housing and case management initiatives focus on high-risk populations, such as people being released from prisons and hospitals.

"OPENING THE BACK DOOR"

"Opening the back door" aims to move people out of homelessness as quickly and permanently as possible. For "crisis" homeless persons, this means helping to smooth the way into existing low-income housing. For those experiencing family homelessness, rapid rehousing uses short-term strategies to help families move out of homelessness and into permanent housing. Rapid rehousing services include supportive services to identify housing, short-term financial and rental assistance, and addressing barriers to stable housing. For those experiencing chronic homelessness, the Federal Strategic Plan has endorsed Housing First Permanent Support Housing. Permanent Support Housing combines subsidized housing with on-site or closely linked supportive services, including physical and mental health care, substance use treatment, case management, and vocational services. Housing First models minimize barriers to housing access, by eliminating conditions like sobriety or engagement in treatment.

OUTREACH AND ENGAGEMENT

Caring for homeless patients includes reaching out to homeless persons who are not currently engaged in care. This may be direct provision of health care by nurses, nurse practitioners and physician assistants, and physicians at alternative sites, or by using case managers or peer counselors who do outreach. The range of services provided at these sites can vary widely, ranging from full-service clinics to nursing stations in which homeless persons can receive basic health assessments, over-the-counter remedies, and referrals. Many programs do not attempt to provide primary care, instead providing urgent care services that function as a bridge between patients and the mainstream health-care system. Often other services are offered to homeless persons as a way of both providing them needed services and engendering the trust that will assist in outreach efforts; for example, providing benefit counseling, mental health services, case management, food, or toiletries.

INTENSIVE CASE MANAGEMENT

Intensive case management is a system of care adapted from models developed for use in the severely mentally ill. Although models differ slightly, intensive case management involves a multidisciplinary team including social workers, nurses, physicians, vocational workers, and others who provide ongoing integrated care for hard-to-reach patients. Intensive case management principles include client engagement, having a low provider-to-client ratio, 24-hour availability of services, and a multidisciplinary team.

RESPITE CARE

Much of the health care that formerly was delivered in inpatient settings (e.g., oral antibiotics for treatment of uncomplicated pneumonia and kidney infection, surgical procedures, chemotherapy) is now done in outpatient settings. Unfortunately, homeless persons cannot receive these services while staying on the street or in basic emergency shelters. Respite care is short-term housing for homeless persons who are either recovering from hospitalization or are receiving medical care for a condition that renders them too ill to be living on the street or in emergency shelters, but does not require hospitalization.

Models of respite care vary widely, but all include shelter (where homeless persons can stay all day), meals, basic nursing care, and access to medical care. Most also provide some form of case management to assist homeless persons obtain complete medical care and other necessary services, including housing, mental health care, and substance abuse treatment. Respite services appear to reduce future hospital admissions, inpatient days, and readmissions.[37]

HEALTH CARE FOR THE HOMELESS NETWORK

One approach to delivering comprehensive health care for the homeless has been the creation of a network of Health Care for the Homeless (HCH) sites that provide both required services and optional programs targeting the needs of the homeless. Required services include primary health care, outreach, substance use treatment, mental health treatment, case management, eligibility assistance, emergency services, referral for inpatient hospitalization, and housing assistance. Optional features include restorative dental services, vision and eyewear services, specialty care, complementary and alternative medicine, employment, and job training and respite care.[38]

All systems caring for homeless patients should seek to emulate the HCH network's principles of care. These include taking services directly to homeless people, arranging transportation for follow-up or other necessary services, provision of services without regard to ability to pay, and collaboration with other agencies to provide comprehensive and coordinated services.

GUIDELINES FOR THE CLINICAL ENCOUNTER WITH THE HOMELESS PATIENT

Mr. Jones has had an elevated blood pressure noted on many occasions and had been started on hydrochlorothiazide. When he returns to the clinic after 6 months, having missed several appointments, he tells you that he has stopped his medication because of urinary frequency. On further screening at that visit, he is found to have posttraumatic stress disorder and admits to consuming a large amount of alcohol on an almost-daily basis and smoking cigarettes daily.

HISTORY TAKING AND PHYSICAL EXAMINATION

Health-care providers can take several steps to improve the care that their homeless patients receive (Table 28-2). In general, management of illness for homeless individuals is similar to that provided to patients who are housed. These patients' competing priorities for basic needs, flexibility, and the use of community resources are critical features of an integrated management plan (Box 28-1).

Homeless persons should be asked the standard historical questions. In addition, all patients should be asked about their current and prior housing status; specific medical conditions found more commonly in homeless persons (e.g., asthma, hypertension, HIV, mental illness); current alcohol, tobacco, and drug use; and any history of abuse or violence. Patients also should be asked if they have a regular source of medical care, if they have any medical insurance, and about their impressions of their prior health care. All patients should be screened for conditions with a higher prevalence among the homeless. These include substance use, mental illness, sexually transmitted diseases, and victimization. Health-care providers should consider screening homeless individuals aged 50 years and older for cognitive and mobility impairments.[29]

In addition, providers should update contact information, including the number of a family member or friend with stable housing where mail or messages may be accessed and who could be contacted in case of emergency.

If the patient is currently staying outside or in a homeless shelter, the patient should be asked specifically how long he or she has been without an indoor place to stay and how many different times he or she has been without an indoor place to stay. In addition, providers should inquire whether there is a place to stay during the day; a place to obtain, prepare, and store food; and about access to water, toileting, showering facilities, and a refrigerator. Finally, questions about personal safety should be asked, given the high rates of victimization common in the homeless population. Answers to these questions are imperative to the construction of a treatment plan based on logistic issues raised by the patient's social context and in agreement with the patient's capabilities and desires.

For homeless women, it is important to reduce obstacles to contraception: having medications and devices onsite, use the Quick Start method, and do not make prescription of methods contingent on PAP smear results (see Chapter 34).

When performing a physical examination, special emphasis should be placed on conducting a dental assessment and foot and skin examination, given the higher prevalence of these problems in homeless persons.

For Mr. Jones—the chronically homeless man with alcohol disorder, tobacco dependence, hypertension, and posttraumatic stress disorder—the clinician should focus on establishing trust, addressing underlying psychiatric and substance use issues, assessing the patient's readiness for smoking cessation, and finding a medication regimen

Box 28-1. Common Pitfalls in the Evaluation of the Homeless Patient

- Not considering the patient's housing status in the assessment and plan
- Not identifying and addressing the competing priorities that interfere with health-care compliance
- Failing to offer preventive measures at every visit
- Developing care plans that are not realistic for patients
- Not detecting and addressing substance use and psychiatric illness
- Not coordinating care with other members of the health-care team
- Not being aware of or discussing community resources
- Not addressing smoking cessation at every visit

Table 28-2. Management of Homeless Patients

Ask patients about their housing status at every visit.
Understand competing priorities and attempt to work around them.
Recommend risk reduction when possible.
Engage patients in developing treatment plans.
Keep regimens simple (e.g., once-daily medications, consider side effects, avoid laboratory monitoring when possible).
Offer health promotion and disease prevention at each visit.
• Annual PPD testing
• Pap smears and sexually transmitted infections (STI) testing per recommendations
• Vaccinations (influenza, Pneumovax, hepatitis A and B, and tetanus vaccine)
• Contraception
Access community resources to assist with developing and delivering a care plan.
Screen for conditions common among the homeless (including tuberculosis, psychiatric illness, and substance abuse).
• Foot care
• Dental referral
• Needle exchange referral

that is realistic based on the patient's chaotic life: If the hypertension is to be addressed, a once-a-day drug should be used that does not cause frequent urination. The clinician should offer smoking cessation resources. In addition, the visit should focus on high-yield preventive health interventions, such as vaccinations and purified protein derivative (PPD) testing. More complicated interventions, such as colon cancer screening, may need to be deferred until the patient's social situation is stabilized.

For crisis homeless patients like Ms. Smith, there may be other issues to consider as well.

> Upon talking further with Ms. Smith, you realize that her cousins' house where she is staying has shag carpeting, two cats, and second-hand smoke, as her cousin is a smoker.

Clinicians must focus on the acute medical and mental health issues, as well as help direct patients to resources that could help them regain housing. Ms. Smith's reactive depression and worsening asthma are inseparable from her loss of housing.

HEALTH PROMOTION AND DISEASE PREVENTION

Because of the fragmented nature of care that homeless persons receive, providers should address health promotion and disease prevention at every visit; patients may not be able to attend follow-up appointments. Providers should follow standard health-care maintenance recommendations, including screening for cancers, when feasible. In addition to these, there are some homeless-specific health-care maintenance recommendations, including annual or semiannual screening for tuberculosis using PPD for homeless persons who stay in the street, sleep in shelters, or use food lines, or those who have been in the criminal justice system.

In addition, homeless persons should be offered pneumococcus and hepatitis A and B vaccination; they should also receive an influenza vaccine annually and tetanus shot every 10 years.

Risk reduction practices also should be discussed routinely with patients. They should understand strategies they might use to minimize the transmission of sexually transmitted diseases as well as diseases spread through injection drug use. For example, if readily available and appropriate, information about local needle exchange programs should be distributed to patients who are injection drug users.

SELECTION OF MEDICATIONS

Providers should select medications that are administered once daily, and do not require laboratory checks or refrigeration in order to facilitate medication regimen adherence. Providers should consider the expense of the prescribed medication and its actual availability to the patient. Providers also should consider medication side effects. For example, prescribing diuretics to homeless patients may be problematic for some, given the lack of restroom facilities and the need for laboratory monitoring. Providers should assess any potential obstacles to adherence and address them (see Chapter 13).

DEVELOPING A CARE PLAN

An integrated care plan for homeless patients must ensure that both medical and nonmedical issues are addressed. Eliciting patients' priorities, with the understanding that identifying regular sources of food, shelter, and clothing may be of paramount importance, allows providers to incorporate patients' goals into the treatment plan, develops a stronger therapeutic alliance, and establishes a more successful plan. Linking patients to resources available in the community also improves care. For example, in some communities, outreach workers can visit patients who are staying in shelters or are on the street to evaluate them between clinic visits.

In addition, patients should be encouraged to seek care at sites that offer open access or that can otherwise accommodate unscheduled visits, because prescheduled clinic appointments often are difficult for homeless persons. Finally, using a multidisciplinary approach, drawing on the expertise of social workers, mental health professionals, and substance use counselors, can help both patient and provider.

ESTABLISH A MONEY MANAGER FOR THE PATIENT

Identifying third parties who will take primary responsibility for managing a client's funds may be useful in cases in which an individual is too impaired by cognitive impairments, severe mental illness, or substance use to safely receive his or her check. These "payees" use the client's money to pay standing bills, such as rent and utility, and dispense spending money to clients in small amounts.[38]

CONCLUSION

Despite the challenges, it is possible for providers to deliver high-quality care to homeless patients by understanding the social context in which these patients live and their obstacles to accessing medical care. Providers must collaborate with patients to develop appropriate care plans. Given the transience of this population, providers should discuss health promotion and disease prevention at every visit and should make every effort to adhere to recommended screening guidelines that have been developed

for the general population. In addition, when possible, providers should attempt to develop cost-effective and system-level programs, including multidisciplinary teams, outreach programs, and respite care, to facilitate the care they provide to their patients, because these approaches can improve the outcomes for their patients.

- Homelessness is a medical issue.
- Homelessness can be a cause and consequence of medical problems.
- Homelessness is the consequence of the interplay between structural social problems and personal vulnerabilities.
- Health-care systems often compound the difficulties that homeless patients have in accessing care.
- Prevention of homelessness should be the goal.
- Comprehensive, integrated health care decreases barriers for homeless patients.
- Accessing community resources is important to the care of the homeless.

Institute of Medicine Recommendations for Addressing Health-Care Disparities General Recommendations

- Screen for homelessness or impending homelessness.
  —Do you feel that your housing situation is secure?
  —In the past month, have you slept in an emergency shelter, vehicle, or place not meant for sleeping?
  —Are you staying temporarily with family or friends because you do not have a place of your own?
  —Have you had difficulty paying your rent, utility bills, or food expenses in the past year?
  —Can you live in the place you are currently living for the next several months? Are you concerned about being evicted? If that happens, do you have another place to go?
- Distinguish between acute and chronic homelessness.
  —Assess for how often and how long a patient has been marginally housed or homeless in the past 3 years.
  —Ask the chronically homeless to what he or she owes homelessness.
- Assess for support systems: Even chronically homeless patients may have tightly knit groups of others they rely on.
- Record the most reliable contact information for your patient.
- Screen for substance use, mental illness, and domestic violence.
- Screen for tobacco use and offer tobacco cessation resources.
- Assess patients' current level of safety.
- Assess teeth and feet in routine physical examination.
- Consider touching your patients in a caring, professional manner; most homeless people crave personal connections.
- Screen for tuberculosis.
- Offer health-care maintenance interventions at each clinical encounter.
- Vaccinate for influenza, pneumococcus, hepatitis A and B, and tetanus.
- Review medications: The patient's actual ability to receive the medications—coverage, cost. Adherence: Are medications prescribed once a day? Do they require refrigeration? Are there other storage issues? Is there a need for frequent refills?
- Refer the patient to a social worker and benefits counselor to address whether he or she is receiving appropriate services and benefits.
- Reduce barriers to care. Consolidate services, onsite referral, and medications; prescribe contraception without PAP.
- Validate the difficulty of your patients' lives caused by homelessness.
- Acknowledge and address competing priorities that might affect access to care.
- Advocate for systems changes that can help accommodate homeless patients.

DISCUSSION QUESTIONS

1. Develop a care plan for a homeless woman with newly diagnosed diabetes. What self-management recommendations do you make? With what medication do you start? Are there other resources you can use to help with adherence? Is it reasonable to make dietary recommendations to her?
2. Given your experiences with the medical system, what system-level changes would you recommend to better the care that homeless patients receive? Are there ways to change your own system that would improve the health of your patients?
3. Discuss some of the barriers you have experienced in providing medical care to homeless patients. What principles do you use when developing a medical regimen for a homeless patient?

RESOURCES

Bureau of Primary Health Care: http://www.bphc.hrsa.gov.

Center for Mental Health Care Homeless Services Branch: http://www.mentalhealth.org.

Center for Substance Abuse Treatment: http://www.samhsa.gov.

National Health Care for the Homeless Council: http://www.nhchc.org.

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Chapter 29

Immigrant Health Issues

Margaret Wheeler, MD, Teresa J. Villela, MD, and Susana Morales, MD

Objectives

- Review health issues faced by immigrants.
- Discuss a framework for understanding the health risks of immigrants.
- Describe demographics and other characteristics of immigrants to the United States.
- Review determinants of legal immigrant status in the United States.
- Discuss interventions to improve care.
- Review patient, provider, and system challenges in the care of immigrants.

INTRODUCTION

> Mr. Moraga fled political persecution in Guatemala. He is undocumented, speaks little English, and has been working as a janitor. Many people assume, because he is undocumented, poor, and Latino, that he is also uneducated. He holds a PhD.

Multiple waves of immigration, including the prolonged importation of African slaves, account for the fact that 99% of all US residents are either immigrants or their descendants. Immigrants everywhere in the world are a diverse group, differing in everything from their backgrounds to reasons for immigration. People have migrated to the United States, as they have other places in the world, searching for economic and educational opportunity and fleeing religious persecution, political and social unrest, and personal danger. Consequently, political, economic, geographic, and cultural stimuli and barriers to immigration have shaped the character and experiences of immigrant communities in the United States and globally. Immigrants face increased risks of many illnesses, poor health-care access, and lower-quality health. This chapter reviews these risks and the ways to help mitigate them.

IMMIGRATION: DEMOGRAPHICS

Immigration is defined as resettlement in a country to which one is not native. Immigration is a potent global force (Figure 29-1).[1] Indeed, according to the US census, in 2010 almost 13% of the population was foreign born (Table 29-1).[2]

Immigration into the US during the 1990s reached a historic high, with approximately 1 million persons entering the United States legally per year. Immigration rates have remained high, with one-third of all foreign-born residents arriving in the United States after 2000. All told, there are about 11.7 million undocumented immigrants in the United States.[3] In contrast, the number of refugees (i.e., somebody who is seeking or taking refuge, especially from war or persecution, by going to a foreign country) entering the United States has been going up very slowly despite burgeoning numbers of refugees globally.[4]

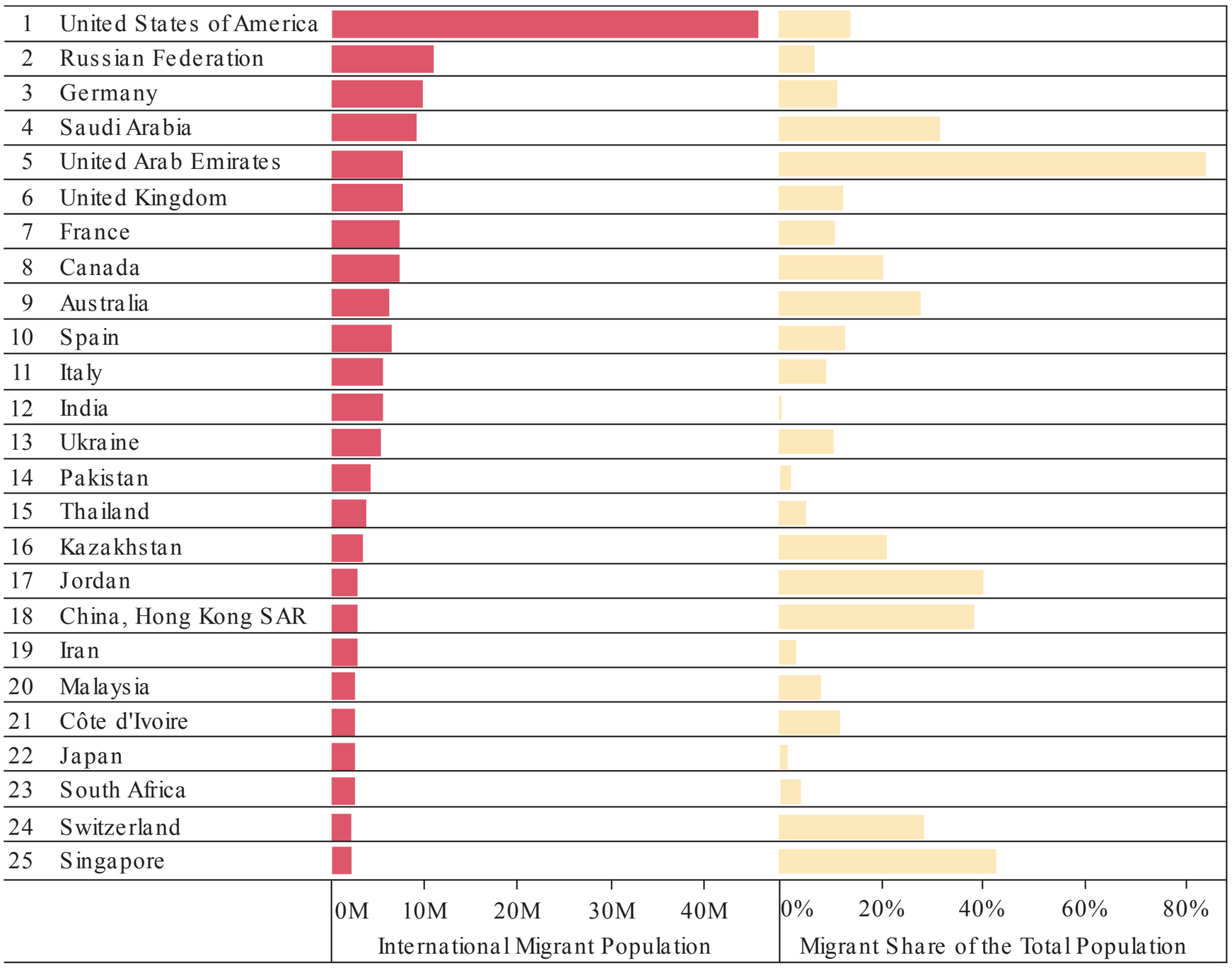


Figure 29-1. Top 25 destination countries, 2013: International migrant population and migrant share of total population.
Source: Migration Policy Institute tabulation of data from the United Nations, Department of Economic and Social Affairs (2013). Trends in International Migrant Stock: The 2013 revision (United Nations database, POP/DB/MIG/Stock/Rev.2013). Available at http://www.migrationpolicy.org/programs/data-hub/international-migration-statistics.

Table 29-1. Foreign-Born Population by Region of Birth: 2010

Region of Birth	Population	Margin of Error[a] (±)	Percent	Margin of Error[a] (±)
Total[b]	39,956	115	100.0	(X)
Africa	1607	33	4.0	0.1
Asia	11,284	47	28.2	0.1
Europe	4817	44	12.1	0.1
Latin America and the Caribbean	21,224	90	53.1	0.1
Mexico	11,711	83	29.3	0.2
Other Central America	3053	46	7.6	0.1
South America	2730	42	6.8	0.1
Caribbean	3731	42	9.3	0.1
Northern America	807	16	2.0	–
Oceania	217	10	0.5	–

X, not applicable; –, represents or rounds to zero.
Note: Percentages do not sum to 100.0 due to rounding. (Numbers in thousands. Data based on sample. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see https://www.census.gov/prod/2012pubs/acs-19.pdf.
[a]Data are based on a sample and are subject to sampling variability. A margin of error is a measure of an estimate's variability. The larger the margin of error in relation to the size of the estimates, the less reliable the estimate. When added to and subtracted from the estimate, the margin of error forms the 90% confidence interval.
[b]Excludes 181 persons who reported they were born at sea.

FACTORS INFLUENCING THE IMMIGRATION EXPERIENCE

> Mrs. Rosas left her children with her mother when she immigrated to the United States. Eventually, her mother and the children are able to come to visit on a tourist visa. While in the United States, her mother suffers a debilitating stroke.

Although recent immigrants have always been a large part of the US population, in the past most came from Europe. Today's immigrants are increasingly diverse, coming mostly from Latin America and Asia. Latin Americans make up 53% of the foreign born, Asians 28%, and Europeans 12%, with the remaining from other regions (link to maps of where immigrants to the United States come from http://www.pewhispanic.org/2015/09/28/from-ireland-to-germany-to-italy-to-mexico-how-americas-source-of-immigrants-has-changed-in-the-states-1850-to-2013/). These categories are so broad that they hide a rich diversity of nationalities, ethnicities, cultures, languages, migration histories, socioeconomic classes, and racial admixtures.[5] This diversity of factors, however, profoundly affects people's experience of immigration and the characters of the communities they form. These communities change with each wave of immigration and each generation of children.

Reviewing a patient's immigration history may help the clinician understand their patients' experience and its possible impact on health. These experiences, as in the case of Mrs. Rosas' family, may be very different for each member. Where someone comes from, the reason for migration, whether they come alone or with family, who and what are left behind, and whether they join an immigrant community are all important. Age, culture, language, education, and legal status are also significant factors to consider (see "Core Competency").

IMPACT OF IMMIGRANTS' LEGAL STATUS

A person's documentation status has a profound effect on access to opportunities and services that affect health. Inquiring about a patient's legal status can help clinicians understand the services their patients are entitled to and the hurdles they must face in everyday life, but must be done with sensitivity. Some patients question the clinician's motives, fearing denial of care, or, even worse, that the health-care provider might turn them into the immigration service. In addition, access issues are complicated when the US-born children of undocumented immigrants are granted citizenship. For example, restricted parental access to public benefits might prevent undocumented parents from seeking help for their legally entitled children.

LEGAL IMMIGRANTS

Legal immigrants are those who have obtained citizenship, have permanent residency status (possess a green card), temporary residency status (are part of an amnesty program), have been granted temporary protected status because of a natural disaster or civil conflict in their country, or are asylees or refugees.

Asylees

Asylees are those who have been granted political asylum from fear of prosecution once they have already entered the United States, and they are typically eligible for citizenship within a year.

Refugees

Refugees, on the other hand, apply to come to the United States from a country to which they have fled, fearing persecution on account of race, religion, nationality, membership in a particular social group, or political opinion in their own country.[6] After a year of entering the United States, refugees are eligible for permanent resident status and after 5 years for citizenship. Victims of "severe trafficking," that is, those coerced into sexual or other servitude, are also eligible for refugee status.

NONIMMIGRANT FOREIGN NATIONALS

Nonimmigrant foreign nationals are those here on visas allowing them to work or study. They must demonstrate an ability to support themselves and claim they do not intend to stay in the United States permanently.

IMPACT OF IMMIGRATION POLICIES

Immigration issues have always been controversial: who and how people are allowed to enter legally, the causes and consequences of entering illegally, and who is eligible for refugee status are political matters. National policies determine who is legally allowed to enter the country and have a powerful influence on their experiences once here.

Before 1980, US refugee policy was heavily influenced by the Cold War. Leaving a communist state was usually sufficient justification for refugee eligibility. The Refugee Act of 1980 based refugee status less on ideology and more on evidence of persecution. Nevertheless, the president can make exceptions to the definition and allow easier access for some. The president and Congress determine the total number of refugees who may be admitted to the United States each year from each of five regions, with separate quotas for each.

The 1996 Illegal Immigration Reform and Immigrant Responsibility Act significantly tightened border restrictions, changed rules on asylum, and restricted immigrant access to public benefits, including for legal immigrants.[7]

This act also legislated specific vaccination and medical examination requirements for immigrants and those seeking permanent residency status. Physicians certified as Bureau of Citizenship and Immigration Services (BCIS) Designated Civil Surgeons must perform these examinations.

IMPACT OF EMPLOYMENT OPPORTUNITIES

Many of those coming to this country, legally and illegally, have come to work. Indeed, new immigrants formed about 50% of the new labor force growth in the country in the last decades, and are thought to have provided a net economic gain for the US economy and for nonimmigrant workers. Approximately 26 million immigrants are in the labor force, accounting for 16% of the civilian workforce in 2014. This represents threefold increase since 1970. As in all other domains, the work immigrants do is very diverse. Thirty percent of immigrants worked in professional or managerial occupations; 25% percent in service occupations; and 30% in transportation, production, natural resources, construction, and maintenance occupations.[8] Twenty-five percent of all physicians,[9] 27% of science and engineering professionals,[10] and 72% of all farm workers in the United States are foreign born.[11] Work in agriculture, meat packing, restaurant industry, and construction, particularly if the worker is undocumented, often places many immigrants at high risk for occupational injury and illness (see Chapter 25).

IMPACT OF OTHER SOCIODEMOGRAPHIC FACTORS

The diversity of immigrants is so great that it is impossible to generalize from population statistics to any one individual. The United States attracts both highly educated and wealthy immigrants, and those who have had few educational or economic opportunities in their own countries. Statistically speaking, immigrants are more likely to be employed, reside in larger multigenerational households, have more children, live in poverty, and lack a high school diploma than native-born Americans. Revealing the diversity of this population, immigrants are also more likely to have a PhD than native-born Americans.[10] Immigrants without a high school diploma from their native lands are especially likely to have severely poor literacy in English.[9]

ISSUES AFFECTING HEALTH-CARE ACCESS AND DELIVERY

HEALTH-CARE ACCESS, UTILIZATION, AND QUALITY

There is a misperception that immigrants overburden the health-care system.[10] Immigrants use public resources at lower rates than native-born populations and have significantly poorer access to health care. For example, prior to health-care reform, 34% of immigrants lacked health insurance, whereas only 12% of native-born US residents were uninsured.[5] Noncitizens receive much lower rates of medical and dental care, and go the emergency room less often. Noncitizen children in non–English-speaking families were much less likely to see a doctor than children who are English-speaking citizens.[12] When they do access medical care, immigrants are also at risk of receiving inadequate care.[12-16] Moreover, it is an underappreciated fact that immigrants, including unauthorized immigrants, contribute significantly to tax revenues supporting services that they often do not use.[16,17]

HEALTH BELIEFS AND EXPECTATIONS

The cultural diversity of immigrants may affect health-care delivery. Immigrants may have culturally based health beliefs that may affect trust and adherence to provider recommendations (see Chapter 14). As with all patients, it is important for the health-care providers to understand the immigrant patient's spiritual beliefs. Immigrants come from many different religious backgrounds, and religious communities are important sources of emotional and social support. Religious values influence health beliefs and values, for example, about modesty, reproductive and sexual matters, and end-of-life care. For example, Muslim women may prefer a female provider, and in fact be unwilling to be examined by a male provider.

Immigrant patients often use alternative or complementary medications, although they may be uncomfortable about revealing this to providers. Latinos are more likely than other ethnic groups to use alternative methods because they are cheaper.[18] Use of home remedies, expectations of medical treatment, and health-care delivery also are often based on patients' experiences in their home countries. For example, some immigrants may expect parenteral treatments such as injections to be administered.

In many countries, medications may be obtained without a prescription, even those considered dangerous or banned in the United States. Medications may be outdated or adulterated. In one study of Asian patent medications available in California, 32% were found to have unlabeled medications, 14% mercury, 14% arsenic, and 10% lead.[19] Immigrants residing in the United States may use some of these medications.[20]

TRUST AND THE PROVIDER–PATIENT RELATIONSHIP

Immigrants may be wary of the health-care system and its personnel. They may fear being asked about their documentation status, being misunderstood (particularly

if they do not speak English), not being able to pay for care, or outright discrimination. Studies have shown that minority patients are less likely to find doctors and health systems trustworthy than white patients. Minority patients report feeling they would receive better care if they were of a different race or ethnicity, feeling they are treated with disrespect, looked down on, and that their providers do not understand their cultural origins and beliefs.[21] Not being able to speak the same language as the health-care provider is also an important impediment to both trust and the receipt of high-quality medical care (see Chapter 31).[22]

HEALTH ISSUES FACING IMMIGRANTS

The health issues facing immigrants are complicated because people are exposed to a many risks (Box 29-1). There is the risk of the diseases and exposures that are prevalent in the country of origin; migration and travel back and forth to the native country itself may pose health risks; and there is the risk of the illnesses prevalent in the adopted country. The communities in which immigrants often live also have health risks of their own: more environmental risks and higher prevalence of some infectious diseases, such as tuberculosis, for example. With greater barriers to medical care, the opportunity to mitigate these risks through health care may also be diminished.

Box 29-1. Health Risks of Immigrants

Risks of home country:
- Health care or lack of it
- Political climate
- Trauma
- Persecution
- Environmental exposure (wood smoke, pollutants, lead)
- Infectious disease
- Genetic susceptibilities
- Different cancer incidence: gastric, hepatocellular, nasopharyngeal

Risks of travel:
- Initial immigration
- Travel back and forth
- Legal, medical, psychosocial risks
- Returning home for medical and dental care

Risks of new country:
- New exposures
- Lifestyles
- Cultural and linguistic differences
- Minority status
- Legal and health systems
- Living in community of immigrants

"PROTECTIVE" HEALTH EFFECT OF IMMIGRATION

Despite adverse socioeconomic indicators, immigrants have been shown to have lower infant and adult mortality rates than nonimmigrant Americans. The causes of this epidemiologic paradox are unclear, but some theorize that strong social networks, traditional diets, and low rates of substance abuse, including tobacco and alcohol use, may be involved.[23-27]

INFECTIOUS AND OTHER DISEASES

Infectious diseases top the list of illnesses that are prevalent in many of the developing countries from which US immigrants come. Tuberculosis, HIV, hepatitis, parasitic illnesses, rheumatic heart disease, and malaria are common problems in those coming from developing countries. Elevated lead levels have been reported in up to 50% of children from many developing countries and are common in immigrant and refugee children and pregnant women.[23] Chronic illnesses such as diabetes, hypertension, and coronary artery disease become increasingly important as people stay in the United States and as urbanization influences the epidemiology in global communities as well.

TRAVEL MEDICINE

Travel back and forth between the United States and their home countries has an impact on immigrants' health. The risk of contracting illness, particularly infectious diseases, is higher for immigrants who are travelling home than for those who are merely tourists.

Immigrants travel under different circumstances than tourists. Common reasons for travel include family responsibilities and emergencies, vacation, and even obtaining medical or dental services that are unaffordable in the United States. Undocumented persons may be deported but return to the United States. Families may be divided by their immigration circumstances and this may be a source of severe stress. In other instances, illness may make travel impossible, creating an added layer of complexity and suffering.

Immigrants who return to visit their home countries are at increased risk of developing travel-related illnesses. Over 20% of the population of the United States is foreign born or children of immigrants. Nearly 50% of US residents who travel abroad are foreign-born immigrants. Health care in the home country may be suboptimal, and those returning to their home country are more likely to seek care in these institutions. In addition, these travelers are more likely to engage in higher risk behavior.[28] They are more likely to visit during pregnancy or with young children, stay for longer periods,

and eat similar to their friends and family or visit ill relatives.[24] Stress-related health problems may be exacerbated by travel or seeing ailing, impoverished family members.[24]

Health-care providers often do not think of immigrant patients as traditional travelers and do not advise and appropriately manage prophylaxis. Recommendations for immigrants traveling to developing countries include treatment for diarrhea, avoiding raw fish, education on malaria prevention, and obtaining pretravel immunizations.[29] These pretravel immunizations may need to include childhood immunizations in unvaccinated adults. Prophylactic medications and immunizations for travel-related illnesses often are not covered by health insurance and the expense may be a barrier to some patients. Hence, malaria prophylaxis and vaccination updating, for example, are more important in these travelers than for those who are merely tourists, but they are less likely to receive them (Box 29-2).[29,30]

MENTAL HEALTH

Many immigrants and refugees may have experienced significant trauma, including civil war, violence, and torture (see Chapter 36). Trauma may occur in the native country, during the journey to sanctuary, and in the new home country of refuge.[31] Researchers have shown that refugees may have high rates of depression, posttraumatic stress disorder, and somatization syndromes.[32]

It is estimated that between 5% and 35% of refugees and asylum seekers have been torture victims. Torture can have a severe impact on the mental and physical health of the victim as well as social well-being.[33-35] Even immigrants without official asylum status are at risk of having experienced political trauma. For example, Central American patients seeking care in California primary care clinics have reported high rates of witnessing of political violence and have psychiatric sequelae.[35]

Immigration itself is a high stress act: People may go to a new nation for a better life, but the adjustments involved in such a transition may be extremely stressful. People may immigrate to improve their family's well-being more than their own. Depressive disorder is extremely prevalent worldwide but may be manifested differently by different ethnic groups, may not be understood as a disease by the patients, and may be more stigmatized in people of different cultural backgrounds. The symptoms of depression may be misinterpreted by health-care providers, who may not, in fact, realize that somatization in some of their patients is related to an underlying depressive disorder. As many as half of depressed immigrants and refugees in the United States are not diagnosed or treated for depression.[36]

Box 29-2. Advice for Travelers Visiting Friends and Relatives to Reduce Risk

For food- and water-borne illness and diarrhea

- Advise boiling water, drinking bottled beverages, and eating peeled fruits and hot foods.
- Avoid high-risk foods such as undercooked, dairy, and raw fish.
- Frequently wash hands or use hand sanitizers.
  - Give anticipatory antibiotics such as ciprofloxacin
  - Lower threshold for typhoid vaccine and hepatitis A vaccine

For malaria

- Malaria prophylaxis—protective clothing, mosquito nets, DEET insect repellant, and chemoprophylaxis as recommended by the Centers for Disease Control and Prevention (CDC).
- Traveler should be warned that malaria prophylaxis purchased abroad may be adulterated or less potent.

For tuberculosis

- Consider purified protein derivative (PPD) testing 3–6 months after return if PPD negative

For sexually transmitted diseases

- Discuss preventive measures (avoid high-risk behavior, purchase condoms).
- Vaccinate for hepatitis B if not immune.

For zoonotic and environmental diseases: schistosomiasis, bites, wood fire, toxin ingestion, use of medical services, etc.

- Anticipatory advice about exposures (avoid animals, avoid sleeping at floor level, wash hands, avoid fresh water, use protective footwear).
- Anticipatory purchase of medications/supplies when necessary, such as inhalers, needles, and prescriptions. Avoid traditional medications.

For infectious illness and not having received complete primary vaccine series

- Review vaccination history—particularly tetanus/diphtheria, polio, hepatitis A and B, measles, and varicella—and vaccinate if no serologic evidence of immunity.
- Immigrant travellers are at higher risk for contracting meningococcemia, typhoid, rabies, so consider more strongly.
- Consider rabies vaccination.

For country-by-country recommendations, see: http://www.cdc.gov/travel/

Source: Adapted from Bacaner N, Stauffer B, Boulware DR, et al. Travel medicine considerations for North American immigrants visiting friends and relatives. JAMA 2004;291:2856-2864.

Immigrant and refugee children too may have posttraumatic stress disorder symptoms, including difficulty in school and unruly conduct. Cognitive behavioral therapy, art therapy, and play therapy may be useful in treating the children, and the schools have a role in detecting and supporting them.[37]

SPECIAL ISSUES THAT MAY IMPACT THE HEALTH AND HEALTH CARE OF IMMIGRANTS

FAMILY RELATIONSHIPS

Most immigrant communities have close family relationships that serve as strong supports, providing an emotional and material safety net. Immigrant families often have a pioneer member or members who come to the new country first and then work to bring subsequent family members. Thus, there are sometimes fractured relationships with families divided by visa and immigration issues, and great yearning for being reunited. Immigrants' income is often used to help family members left behind and sending money home may undermine a person's ability to obtain stable housing or food security. Immigrants may need to return home for intervals of time and may be lonely and isolated. Medical decision making may require consulting family members not living in the United States, particularly in end-of-life decisions.

Caring for elders in the home is often a fact for immigrant families. It may be culturally unacceptable for immigrant families to place elderly relatives in nursing homes. This may place an extra strain on immigrant families who may also lack resources to have additional caregivers for disabled family members.

ACCULTURATION

Acculturation is defined as "the process by which foreign born individuals adopt the values, customs, norms, attitudes and behaviors of the mainstream culture."[38] Immigrant families may experience conflicts because of intergenerational pressures. The first generation may especially adhere to traditional values and the second generation may be more acculturated. Differences of perspective on issues of sexuality, gender roles, intermarriage, and elder care may be particularly challenging.[39]

SEXUALITY AND REPRODUCTIVE HEALTH

First-generation immigrant families may adhere to more traditional values as followed in the homeland, which often include a high value placed on female sexual virtue and virginity before marriage. American-born or raised children may, on the other hand, engage in relationships, resulting in teenage pregnancy with high stress and crisis in the family. Attitudes toward homosexuality may drive gay and bisexual persons to conceal their sexuality.

Many immigrant women may have had poor access to reproductive health care in their home countries, and are less likely to have screening pap smears than other groups. Immigrant women may have had little instruction in human biology and anatomy and thus may know little about pregnancy or sexually transmitted disease prevention.

HIV AND SEXUALLY TRANSMITTED DISEASE PREVENTION

Negotiation about issues of condom use and safer sex practices may be particularly difficult for many immigrant women where discussion of sexual practices even in the context of a sexual relationship may be culturally unacceptable. Demands for condom use may be seen as admissions of promiscuity or linked to low trust in the male partner. Immigrants also may have misconceptions about HIV transmission that interfere with safer sex practices; for example, that condoms do not work to prevent sexually transmitted diseases or HIV; that the withdrawal method is adequate to prevent HIV or sexually transmitted diseases; that a healthy physical appearance rules out infection. Sex with sex workers, especially in men who are socially isolated and far from their wives or girlfriends, may be common. Sex with old lovers or sex workers when travelling home may increase travel risks as discussed earlier.

FEMALE CIRCUMCISION

Female circumcision is practiced in many African countries, across class and religious lines. An estimated 100 million women have undergone various forms of female circumcision (also known as female genital mutilation). Female circumcision is linked to cultural and sexual identity, and cultural norms may strongly favor its practice, but the World Health Organization and other international groups have condemned it (Fact Sheet http://www.who.int/mediacentre/factsheets/fs241/en/).

Female circumcision is much more dangerous than male circumcision, and has both physical and psychological sequelae. It can range from partial to total clitoridectomy to infibulation (excision of the clitoris and part of or all of the labia). Infections, including sepsis and gangrene, as well as other complications have been reported. Women who have undergone this procedure may be reluctant to seek medical care because of fear of stigmatization.[33,40] Fear of genital mutilation is also an accepted reason for women to apply for refugee or asylee status and is recognized by the United Nations High Commission on Refugees as a legitimate reason for doing so (see http://www.refworld.org/docid/4a0c28492.html).

BORDER HEALTH

Nearly 12 million people live along the Mexico–United States border. Border residents live in areas with major air quality, water quantity, and water quality problems.

There are higher rates of infectious diseases such as hepatitis A, salmonella, and tuberculosis (including multi–drug-resistant tuberculosis). People residing in these border regions frequently cross back and forth across the border and may obtain health-care services on either side. Public health and health-care delivery organizations do not routinely cooperate in planning of interventions.[41]

VIOLENCE

Immigrants may have been exposed to traumatic violence in their home countries, but because of poverty and other factors they may be exposed to violence and crime in their adopted country. Hispanics, for example, have much higher rates of death from homicide than do whites.[39] Domestic violence may be an important issue. In New York City, for example, immigrant women have been reported to be at increased risk for mortality in domestic violence.[42] Factors that at play may include fear of approaching the police or judicial system to seek protection from a batterer, fear of the batterer being deported, language and informational barriers about women's rights in the United States, and fear of losing custody of children if domestic violence is identified.

- The diversity of immigrant backgrounds is not recognized.
- Immigrant experiences can vary widely, even within one family.
- Many barriers exist for immigrant patients, such as lack of insurance and low English proficiency.
- Immigrants are exposed to health risks from their home countries, migration, and the United States.
- Health-care beliefs and treatments are heavily influenced by experiences in home countries.
- Immigrants who travel to their home countries do not receive appropriate prophylaxis.
- Immigrants may receive inadequate and worse treatment than native-born Americans.

STRATEGIES FOR IMPROVING IMMIGRANTS' HEALTH

MEDICAL SCREENING EXAMINATION

The Centers for Disease Control and Prevention (CDC) and the Canadian Collaboration for Refugee and Immigrant Health have published guidelines (http://www.cdc.gov/immigrantrefugeehealth/pdf/checklist-refugee-health.pdf and http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3168666/) for the medical screening and treatment of refuges that can be used to guide the treatment of immigrants in general. As conditions for legal immigrant entry, the US government requires screening for infectious diseases and documentation of up-to-date immunization status.

An overview of the recommendations for the medical screening examination is shown in Table 29-2. Specific guidelines for the history and physical exam; immunization schedules; and screening and treatment of tuberculosis, helminths, hepatitis B, sexually transmitted diseases, HIV, lead levels, nutrition, malaria, and mental health of immigrants and refugees domestically and overseas are also published by the CDC (http://www.cdc.gov/immigrant-refugeehealth/guidelines/domestic/domestic-guidelines.html and http://www.cdc.gov/immigrantrefugeehealth/guidelines/overseas/overseas-guidelines.html).

In addition to medical screening, the assessment of an immigrants' complaints, differential diagnoses entertained, evaluation of laboratory findings, and treatments will be

Table 29-2. Recommended Medical Screening Examination: Adult and Pediatric Immigrants and Refugees[44]

Medical
General history
Physical examination
Children: vision and hearing screening
Developmental and nutritional assessment
Preventive health interventions
Immunization status
Tuberculosis screening
Children: safety issues
Laboratory testing
Routine
CBC with differential
Hepatitis B screening (HBsAg, anti-HBsAb, anti-HBc)
Hepatitis A serology
Urinalysis with microscopic analysis
Stool ova and parasites × 3 CDC recommends treatment for refugees from endemic areas with single dose of albendazole
VDRL (screening for syphillis)
HIV
Special
Hepatitis C
Malaria
For refugees from endemic areas of sub-Saharan Africa, CDC treats for Plasmodium falciparum with artesunate combination therapy.
Children and pregnant women: lead levels
Referrals as needed
Psychiatric
Vision and hearing
Dentistry
Psychiatric and behavioral
(Caveat: Screening for trauma may be traumatic in itself and should be obtained within the context of a relationship, and guided by the knowledge that retraumatization can occur in recounting traumatic experiences (see Chapter 36).

Source: Adapted from CDC and Canadian Coalition on Immigrant and Refugee Health: http://www.cdc.gov/immigrantrefugeehealth/pdf/checklist-refugee-health.pdf; http://www.cmaj.ca/content/suppl/2010/06/07/cmaj.090313.DC1/imm-summary-2-at.pdf.

more accurate if interpreted in the context of the patient's epidemiologic risks based on the immigration history. In an immigrant, for example, eosinophilia is a common manifestation of an undiagnosed parasitic infection and neurocysticercosis is not an unusual cause for seizures. Genitourinary tuberculosis might be the cause of infertility and schistosomiasis the cause of hematuria. Even likelihood of certain cancers, gastric cancer, for example, is increased in certain immigrant groups.

IMPROVE PATIENT–PHYSICIAN RELATIONSHIP

Multiple issues may affect relationships between physicians and immigrant patients: language barriers, cultural barriers and misunderstandings, mistrust, or inability to pay for treatments. Despite all these possible impediments, immigrant patients also tend to be very grateful for attempts made to accommodate them. Inquiring about each individual's experiences of immigration, health-care beliefs, and practices rather than making assumptions based on demographic probabilities is vitally important. Finding out a little about the places, political situations, and history of the countries from which patients come can enrich the experience for both patient and provider. Health-care providers are often held in high esteem and are honored with intimate confidences. Hearing these confidences and bearing witness to the travails of patients who have left or fled their homes is both an exceptional privilege and an opportunity to decrease suffering.

PRACTICE LEVEL INTERVENTIONS

Reflecting the diversity of the communities served through art work, accommodating non–English speakers, and having a diverse staff are ways a practice can welcome immigrant patients. Having appointment times that are more convenient for work schedules and financial accommodations or pharmaceutical plans for those without insurance or medication coverage will help increase chances that patients will come back and take prescribed medications. Having social workers and health educators on site is also useful. Developing practice expertise in issues facing specific groups can improve care as well. For example, in Boston, one physician set up a referral clinic for women who had been circumcised. A rich network of referrals to everything from community-based organizations to immigration lawyers and low-cost dentists will help address the full panoply of issues facing immigrant patients.

Community-based primary care practices may enhance immigrant patient access to care, compared with hospital-based outpatient departments. Immigrant patients may have difficulty accessing specialty services. Instructions and consent forms for diagnostic tests and procedures often are not translated into other languages. Institutions may lack bilingual/multilingual signage and thus become labyrinths for immigrant patients. As a result, care must be taken to facilitate specialty care and diagnostic services for immigrant patients to avoid improper or inadequate informed consent or dangerous errors in preparation for procedures (e.g., not fasting; not holding anticoagulants). The use of community health promoters or advocates may enhance the ability of vulnerable immigrant patients to navigate the health-care institution and system.

HEALTH-CARE SYSTEM LEVEL INTERVENTIONS

Enrolling eligible patients in publicly funded health plans to expand access to care is an important step. New York City's presumptive eligibility experiment after the September 11th tragedy (computers were damaged so that presumptive Medicaid eligibility was granted pending later verification) resulted in many patients obtaining needed services. A retrospective analysis showed little if any fraudulent enrollment. Thus, streamlining enrollment procedures was extremely efficacious in expanding access to care.[43] A simple and streamlined form is essential for enrollment in the Children's Health Insurance Program (CHIP) and other expanded access programs. Outreach to immigrant populations is also important in enrollment, as has been seen in the CHIP programs nationally.

Alameda County in California instituted the "No Wrong Door" project, an innovative program to insure all uninsured persons in the county regardless of immigration status (www.alamedahealthconsortium.org). A variety of programs are used to obtain coverage, such as Medi-Cal, Healthy Families, and other affordable, low-cost coverage plans for low-income families. Health promoters provided community outreach and navigation of the health-care system and enrollment process.

COMMUNITY LEVEL INTERVENTIONS

Providers, practices, and health-care systems might also focus on immigrant communities rather than on individual patients to improve health. These efforts might take the form of media campaigns or partnerships with community-based organizations focusing on particular issues. Media campaigns have targeted smoking cessation or HIV screening in immigrant populations. Programs training health promoters in areas as diverse as healthy eating for patients with diabetes to screening for hepatitis, domestic violence, and cervical cancer have been shown to be successful in immigrant communities.

CONCLUSION

Immigrants are a large and diverse segment of the US population with wide-ranging health risks and needs. The stimuli and barriers to immigration; national and

international politics; and personal characteristics and histories mold the immigration experience. Immigrants face increased risks of many illnesses, poor health-care access, and often lower-quality health. Recognizing and attempting to understand the variety of factors that impact immigrant health will improve the health of individual patients as well as US communities.

- Immigrants come from very diverse backgrounds.
- Remember all important family members may not reside in the adopted country.
- Assess for all risks: home country, travel and adopted country.
- The possibility of torture should be considered in any refugee.
- Conduct culturally competent patient education.
- Develop culturally competent providers and institutions.
- Address patient concerns respectfully, and elicit concerns.
- Use trained interpreters for limited English proficiency patients.
- Screen for common infectious diseases and mental health disorders.
- Remember that immigrant travelers are high-risk travelers. Advise, provide appropriate prophylaxis, and vaccinate accordingly.
- Assess the community for resources and referral.
- Be aware of access to care problems.
  —Work with community outreach groups.
  —Help with navigation of resources.
  —Consider costs.

Taking the Immigration History

Explore the patient's life history and psychosocial context.

- Does the patient use treatments or healers from the home country?
- Assess for communal decision making. Is the family a source of strength and support?
- Inquire about home remedies and alternative medical treatments.
- What is the patient's religious background, involvement in the religious community, and other community supports?
- Have there been any occupational or environmental exposures?
- When did the patient last travel abroad or to the homeland? How long was the stay?

Psychosocial assessment of immigrants and refugees

- Ask about health beliefs; do not stereotype.
- Ask how this might affect medical care, such as end-of-life issues and treatment.
- Screen for depression, anxiety, posttraumatic stress disorder (e.g., taking a complete trauma history) and examine the patient for physical findings of torture.

Ask about immigration status

- Ask about reasons for immigration, hardships endured, barriers, or returning plans and patterns.
- Where is the patient from?
- How long has the patient been in the United States?
- Why did they come?
- Where did the patient live before arriving here?
- Who is still back home?
- Who does the patient live with here?
- How does patient support him- or herself?
- Consider a referral to an immigration lawyer if permanent residence is desired.

DISCUSSION QUESTIONS

1. Discuss the barriers to access to care faced by immigrant patients.
2. Describe health problems faced by immigrants and refugees.
3. You are practicing in a community populated by refugees from a developing country. How would you set up a culturally competent practice to care for this community? What barriers to access would you target and how?

RESOURCES

Asian and Pacific Islander Health Forum: http://www.apiahf.org/.

Association of Asian Pacific Community Health Organizations: http://www.aapcho.org/.

Diversity Rx: Promoting language and cultural competence to improve the quality of health care for minority, immigrant, and ethnically diverse communities: http://www.diversityrx.org.

Center for Disease Control Travel Health: http://wwwnc.cdc.gov/Travel.

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Migrant Clinicians Network: http://www.migrantclinician.org/.

Future of Children. Publication devoted to issues of immigrant children put out by Woodrow Wilson School of Public Policy at Princeton and the Brookings Institute: http://www.futureofchildren.org/futureofchildren/publications/journals/journal_details/index.xml?journalid=74.

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National Immigration Law Center: http://www.nilc.org/.

NHeLP: National Health Law Program: http://www.healthlaw.org.

National Library of Medicine's Asian American Health Page: http://asianamericanhealth.nlm.nih.gov/.

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Chapter 30

Rural Health Care: Communities, Systems, and Patient Care

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Objectives

- Describe the demographics and characteristics of rural patients.
- Identify common vulnerabilities among rural populations.
- Outline the health issues faced by rural Americans.
- Review the unique relationship between rural living and health.
- Highlight challenges to care of rural patients from the perspective of the individual provider and the health system.
- Discuss strategies and initiatives to improve health care of rural residents.

INTRODUCTION

"Rural" is a term that elicits a variety of meanings and images such as farms, expansive landscapes, or small towns. For some, it is a state of mind or a feeling. Others contend its definition is quantifiable by population density or other measures. Although there are many definitions, all attempt to describe something socially and geographically different from urban areas.

The number of Americans living in rural areas has been declining; however, their numbers are substantial. The 2010 US census reported 19% of the population lives in rural areas and 75% of the US landmass is nonmetropolitan.[1] Globally, 3.4 billion people, or just under half of the world's population, live in rural areas.[2] Within rural populations, there are many who struggle with health and health care. This chapter identifies and discusses some of the vulnerabilities and health challenges specific to rural populations, the context of rural health systems, and key issues for health-care providers in rural communities.

RURAL LIVING

The social fabric of rural communities is complex and can vary greatly. The smaller scale of rural towns can frequently facilitate an interconnectedness and reciprocity among its inhabitants. People living in small towns tend to know their neighbors and interact with them in multiple settings. This interconnectedness lends itself to grassroots responses to local issues. Community action is frequently organized through churches, civic groups, and local government. These institutions and their leadership can often set the agenda for civic priorities.[3,4] It is no surprise that community-oriented primary care, with its focus on broad community needs that are fundamental to health, has its roots in rural health.

Although there are pockets of prosperity and economic growth in rural communities, many rural economies are on the decline. In recent decades, particularly in developing countries, people are migrating from rural areas to urban centers. This rural flight is spurred by the lack of economic opportunities in rural areas and the perception

that larger cities hold the promise of better jobs and more educational opportunities.[5]

RURAL POPULATIONS AND HEALTH INEQUALITIES

Concentrated poverty, low education levels, and hazardous occupations have been major contributing factors in the health inequalities found in rural places compared to urban cities. In line with global trends, rural Americans experience a significantly higher mortality rate than those living in urban areas.[6] Although activities such as mining, agriculture, and farming are on the decline, they are exclusively rural industries, and they are among the most hazardous occupations. Each year, for example, approximately 10% of farmers are injured while working; their injuries are often multiple and severe, resulting in death or substantial disability.

Obesity is another challenge for rural Americans. Rural populations are 20% more likely to be obese compared with those living in urban areas.[7] Some studies have indicated that rural people have a diet that is higher in fat and consume fewer fruits and vegetables. Ironically, rural communities, often the producers of fruits and vegetables, have less access to healthy foods than urban areas.[8] Rural people have to travel farther to grocery stores, where there is frequently less of a selection of fresh foods compared with urban areas.

The lack of physical activity is another contributing factor to rural obesity in the United States. Rural people tend to exercise less than urbanites.[9] Some researchers believe physical isolation is one barrier to regular exercise. Rural areas often have sprawling settlement patterns, encouraging people to walk less and drive more. Rural school children, for example, are more likely to ride the bus than walk to school. Sidewalks and trails also tend to be less prevalent in rural areas, reducing the opportunity to walk safely to local destinations; exercise facilities and sports teams may also be less accessible.[9]

Suicide represents another significant health disparity for rural America. Since the 1970s, rural counties have experienced a significantly higher suicide rate compared with urban areas. Risk factors for suicide such as depression, isolation, economic worries, and alcohol are exacerbated by the relative dearth of mental health care. Rural gun culture is also widely believed to contribute to the suicide disparity: three out of four suicides in rural America involve firearms.[10]

SPECIAL POPULATIONS IN RURAL HEALTH

Similar to urban areas, rural America is a dynamic and constantly evolving social and economic landscape. Creating accessible and equitable health systems has been a major challenge for rural counties that have experienced this recent and dramatic demographic trend.

Although each rural community represents a unique social amalgamation of waves of migration, there are some distinguishable national trends. Hispanic migration to rural areas has dramatically changed the cultural composition of many rural communities, and since 1980 the number of Hispanics living in rural America has more than doubled.[11] Migrants from Mexico, Central America, and the Caribbean provide a much needed labor force for agricultural industries and contribute to small town economies. While this migration began in the southwest, it now encompasses all continental states and Alaska.

Many Hispanics, particularly those working as migrant agricultural laborers, face significant barriers to health and health care. Language barriers may prevent them from effectively navigating social or clinical institutions. They often live in poverty, have substandard housing, and may be further marginalized if they are undocumented immigrants. Educational opportunities for the children of migrant workers are also limited and few obtain higher educational degrees.[12] The health consequences of these upstream factors cannot be understated.

American Indian (AI) and Alaska Natives (AN) are other populations with unique histories and special health needs in rural America: many AI/ANs are committed or constrained to living in rural areas, almost all reservations are located in rural areas, and most of the tribal governments own rural land. The percentage of AI/AN adults living in poverty is among the highest compared with other racial/ethnic groups, and housing conditions for many Native Americans are substandard.[13] Native Americans have lower life expectancies and worse health statistics than any other ethnic group in the United States. AI/AN have higher mortality rates from tuberculosis, chronic liver disease and cirrhosis, accidents, diabetes, pneumonia, suicide, and homicide compared with other racial and ethnic groups.[14] These trends date back to the historical trauma experienced when contact was made with European settlers, subsequent inequitable treaties, and dislocation to reservations. Additionally, cultural barriers and geographic isolation have added further obstacles for AI/AN populations to receiving adequate health care.

Rural communities are aging. The proportion of US residents over 65 years old is 14.6% in rural areas compared with 11.9% in urban areas.[15] The rural elderly are largely nonminority, less educated, poorer, and more likely to live in substandard housing compared with metropolitan elderly. Rural communities lack specialized transportation and geriatric services, resulting in special health challenges for the elderly and the providers that care for them.

RURAL HEALTH-CARE ACCESS AND SERVICES

CORE ELEMENTS OF RURAL HEALTH DELIVERY

At least three core elements provide the basis for a stable rural health-care system: strategically placed and stable hospitals, clinics, and support services; adequate health professions workforce; and sufficient health-care financing. Political commitment and policy interventions targeting these elements are essential to maintaining viable rural health-care systems in the United States and globally.[16]

Hospitals, Clinics, and Ancillary Services

The economic and community value of hospitals, clinics, and other health-care services are critical factors in linking together the various components of the rural health-care system. In addition, rural hospitals are often the largest employer in the community and play a substantial role in recruiting and retaining physicians and other health-care professionals. Communities that have stable and adequate health-care services also become magnets for other new businesses, recreation, retirement, and referrals to ancillary health services.

The vitality of hospitals to rural communities became apparent in the 1980s in the United States, when reduction in Medicare payments, coupled with a slowing economy and population movement away from rural areas, contributed to the collapse of 160 small and rural hospitals.[17] The effect on these communities was so devastating that Congress responded by providing grants to develop rural health networks, to regionalize services, sustain local emergency medical system (EMS), and increase quality of care. The Critical Access Hospital (CAH) program was one of the initiatives that sought to stabilize the financial impacts on rural hospitals and reverse some closures that had left communities without adequate access to hospital-based services.[18,19] To be designated a CAH and eligible for enhanced reimbursements, hospitals had to be located in a defined (federal or state) rural areas; be 35 miles distant to the next closest acute care hospital (or 15 miles if the roads were through mountains or poorly maintained); have 25 acute beds maximum; and maintain an average annual 96-hour length of stay for admissions.[6]

CAHs have played a significant role in consolidating services in rural communities. Physicians have increasingly merged their practices with hospitals to lessen the administrative burden of federal and insurance compliance and reimbursement policies, and to allow them to focus more on patient care. In addition, the hospital-associated clinics have applied for designation as federally supported Community Health Clinics (CHC) or Rural Health Clinics (RHC) in order to receive supplemental federal payments for clinical services provided in rural locations.

These federally supported clinic systems have also been vital for improving access to health care in all underserved areas, especially rural ones. CHC, Migrant Health Clinics, Health Care for the Homeless Clinics, and Public Housing Clinics, all also known as Federally Qualified Health Centers (FQHC), are one system that provides much of the care to rural communities. About one-half of FQHCs are located in rural areas. They serve one out of every seven US rural residents, about 10 million people.

RHCs, like FQHCs, were created by Congress to enhance access to medical care. RHCs differ from FQHCs in that they do not target specific underserved populations, but rather increase access to rural areas that are identified as health professions shortage areas (HPSA). RHCs can be either independent (free standing) or provider based (as part of a hospital or nursing home) and are reimbursed for Medicare and Medicaid services through an all-inclusive rate rather than fee-for-service or prospective payment.[8] Key elements for certification as an RHC include being in a nonurban area, being located in a federal/state designated HPSA, and employing physician assistants (PA), nurse practitioners (NP), certified nurse midwives (CNM), or licensed psychologists for at least 50% of the time the clinic is open for services.[9] Indeed, RHCs provided the first federal initiative to recognize PAs, NPs, and CNMs and to encourage their use in expanding access to health care.

Health Workforce—Meeting the Needs of the Future

Doctors and health-care facilities are distributed unequally in all regions of the world, with rural areas suffering particularly from maldistribution issues. Seventy-seven percent of rural counties in the United States are designated as HPSAs and, conversely, 65% of all HPSAs are rural. Impending attrition in medicine, nursing, and dentistry as large blocks of providers reach retirement age in the next decade; declining interest in primary care disciplines; and inadequate teaching and clinical training resources are likely to compound this problem. Policymakers in the United States and globally have focused on multiple strategies to address the imbalance from providing grants and incentives to subsidize health-care systems and attract providers, to expanding the nonphysician health provider workforce.

A cornerstone to any rural health-care system is a solid base of primary care providers—primarily family practice physicians, supplemented with PAs and NPs. Details of the projected primary care shortfall are documented in multiple federal and professional association studies within the past several years, and although there may be differences in absolute numbers, there is no quarrel with the outcome—the United States[20,21] will be short between 20,400 and 124,000 primary care physician Full Time Employments (FTEs) by 2025. Rural areas are likely to be the hardest hit by this shortfall. Furthermore, the

decline of interest in family medicine will have significant and disproportional impacts on rural communities since family physicians are the largest segment of primary care physicians practicing in rural areas.[22]

PAs and NPs, health professions established in the early 1960s as a response to the shortage and maldistribution of physicians, particularly in rural and underserved urban areas, have since increased their training programs and graduates, and now serve in every medical discipline and health arena. Indeed, both professions are increasing the number of programs and graduates at a much faster rate than medical schools[20] and have projected growth rates of 58% and 30%, respectively, between 2010 and 2020. For example, in 2013, there were 181 accredited PA programs with approximately 5971 graduates. Sixty more programs are currently pending accreditation through 2020, and that number may yet increase as demand grows. There were 84,064 practicing PAs in 2013 and projections are for an increase[23] up to 125,847 by 2026.

PA and NP providers fill the gap created by the continuing shortage of primary care and rural physicians: 34% of primary care providers in rural areas are PAs and NPs, and they comprise 46% of the provider base in community health centers. Slightly more than one-third of PAs and a little more than half of NPs are in primary care with approximately 14% and 18%, respectively, practicing in rural locations. Osteopathic physicians and international medical graduates (IMG) also select rural practice more frequently than allopathic physicians (18% and 13%, respectively, versus 11%).[24]

Since the "barefoot doctors" deployed in China over 50 years ago, use of community health workers (CHW) has been an important strategy to improving health-care access in rural areas. CHWs are typically lay people provided with some medical training who help implement specific health-care interventions. For example, CHWs have been shown to improve rates of immunization and breastfeeding, TB treatment outcomes, and reduce child morbidity and mortality.[25] Used extensively in lower- and middle-income countries, use of CHWs is now being adopted in the United States as well.

FUTURE STRATEGIES TO INCREASE THE RURAL HEALTH PROFESSIONS WORKFORCE

Studies of strategies to increase the rural health professions workforce in the United States and internationally have consistent recommendations: broaden the medical student applicant pool to include more rural students; increase the emphasis on primary care/family medicine; provide training opportunities with rural providers and practices through medical school and residency; and provide practice and financial incentives (such as loan repayment and enhanced reimbursement) to attract and retain health-care professionals.[22,26]

An intervention used in many countries is to require medical students or graduates to complete national or rural service commitments as part of their educational or licensing requirements. In the United States, the National Health Service Corps (NHSC) was created to improve the distribution of health-care providers by offering financial support to physicians, PAs, NPs, pharmacists, nurses, and mental health providers who choose to work in rural and other underserved areas. Since 1972, more than 37,000 health professionals have served in the corps, with more than 7500 primary care providers currently in NHSC-supported positions. The NHSC is also creating a system to support its clinicians with training resources and a virtual community specifically designed for providers serving in isolated settings.

Other federal and state initiatives target increasing rural medical educational opportunities, recruiting people from rural communities into the health professionals and increasing the numbers of IMG who practice in rural areas. IMGs comprise about 25% of the primary care workforce in the United States and in some regions are more likely to practice in rural areas than US trained doctors.

Telemedicine

Telemedicine, defined by the Institute of Medicine in 1996, as "the use of electronic information and communications technologies to provide and support health care when distance separates participants," is a rapidly evolving field.[27] It comprises a diversity of clinical practices and technologies that hold much promise for improving care, particularly specialty care, for rural patients. Currently, three broad categories of telemedicine are being used: (real time) interactive services, remote monitoring, and store-and-forward consultations.

- Interactive telemedicine services provide real-time face-to-face interactions between patients or primary care providers and specialists and back-up physicians. Issues of responsibility, reimbursement, ethics, and effectiveness of these new technologies are just now being elucidated.
- Remote monitoring, or self-monitoring, allows medical professionals to technologically monitor a patient's clinical status. Blood pressure cuffs, glucometers, ECG monitors, scales, and other devices can transmit clinical information that can be used to tailor interventions, thus obviating the need for a patient to travel long distances.
- Store and forward telemedicine involves transmitting medical data (such as medical images) to a physician or medical specialist for review. It is common among specialties such as dermatology, radiology, and pathology where a delay in the specialist's assessment is acceptable.

Access to Facilities and Services

Other criteria for adequate access to services are geographic proximity, availability of services, and ability to pay for services. Mountains, rivers, road and weather conditions, and transportation are key elements in defining access in rural communities.

> Ferry County, in Washington State, is considered one of the most isolated regions; three-fourths of its land mass is federal/state lands. Republic is the main population center and has a critical access hospital and rural health clinic. Bounded by the Canadian border to the north, mountain ranges with sketchy passes in winter to the east and west, and the Columbia River to the south (which requires a short ferry ride to cross), access into and out of this community can be challenging. Often, and depending on weather conditions, helicopter transport is the only way to move critical patients to a tertiary hospital.

In many rural areas, services such as hospitals, clinics, and ancillary services are consolidated in larger communities such as the county seat. Public or private transportation then becomes a factor, as many areas no longer have routine bus service, and poorer populations may not have either a vehicle or gas to attend to care outside their area. Services such as home health, rehabilitation, chore service, physical therapy, and other modalities necessary for comprehensive patient care may also not be readily available. Federal and state programs that target special populations—children and the elderly, for example—may not have capacity for outreach to parts of the community who might be otherwise eligible. Lack of advanced technological and computer systems, cellular phone, and Internet access may also make access to emergency services, telemedicine systems, diagnostic testing, and educational materials more difficult.

Access to Health Insurance

In looking at rural population data, it is frequently noted that many people do not have health-care insurance, a significant barrier in accessing services. Rural populations tend on average to be older, poorer, and have lower levels of education—all of which can contribute to a lower health status and a higher need for health care. The 2010 US census shows there are 49.9 million people without health insurance in the United States—16.3% of the population census 2010 shows that nationally, the metropolitan uninsured rate is 19% overall, while the non-metro rate (communities under 2500 population) is considerably higher at 23%. There are multiple reasons why there are fewer insured individuals in rural areas. Many small businesses cannot afford to pay full benefits for their workers. Some rural jobs are seasonal and/or require only part-time work and therefore are not covered for benefits. Extended benefits to family members, dental coverage, and sick leave are also less often available to workers.

EMERGING TRENDS IN RURAL HEALTH CARE

The Patient Protection and Affordable Care Act of 2010 (ACA) has had a transforming effect on the nature and direction of health care on multiple fronts. Far reaching and rarely discussed segments of the ACA include initiatives important to rural health delivery, including workforce, technology, information systems, financing, and a greater emphasis on patient engagement and responsibility. For rural systems and communities, the impact will hopefully be positive overall, but there will certainly be stresses as well, since operating margins are much thinner and resources are fewer than those in urban systems.

More models of successful telemedicine are emerging in areas such as mental health, dermatology, and emergency medicine. Multiple governmental agencies actively seek new proposals for innovation in this promising area.

While technology promises improved communication and coordination of care that is important to patients, providers, and systems as a whole, it brings real challenges to rural entities (Box 30-1). Increased costs for implementing technology, patient and quality monitoring requirements, and additional staffing push the financial limits for many rural hospitals and clinics. This is an issue as planned federal/state reimbursements are reduced. Information technology (IT) security for medical records and EMR implementation are very costly and the return on investment in this and other technology remains unknown.

Box 30-1. Health Risks and Benefits of Living in Rural Communities

Risk	Benefit
Isolation and more difficulty with privacy Stigma for social problems	Tightly knit communities
Higher rates of poverty, lower educational attainment and employment opportunities	Lower cost of living
More difficult access to care of all sorts due to less availability of services and providers, geography, and insurance	Health-care providers function as part of the community
More suicide, obesity, injury, chronic disease, cancer; higher mortality rates	

Pros	Cons
• Deep relationships with patients • Caring for friends and neighbors • Attachment to community • Breadth of practice • Relative autonomy • Participation in community leadership • Opportunities for loan forgiveness • Lower cost of living	• Lack of anonymity • Few support services • Practicing out of comfort zone • Likelihood of more frequent call • Potentially lower salary • Fewer job opportunities for spouses

CARING FOR RURAL POPULATIONS

Rural areas have higher rates of mortality and disability when compared with urban populations and their health lags behind the country as a whole. The burden of chronic disease is higher in these communities, and while the diseases often look the same as those seen elsewhere, there are special considerations that make the disease burden more profound. These include factors related to lifestyle, economy, and health-care access. Rural minorities face additional challenges with higher rates of chronic disease, hospital admission, and inpatient deaths. Lack of access to preventive services also plays a role in poor health among rural populations: data show lower levels of age-appropriate cervical cytology testing, mammography, colorectal cancer screenings, and adult vaccination rates. Decreased access to specialty care, lack of insurance, minority status, and increasing rurality exacerbate these disparities.

CARE OF THE RURAL EMERGENCY PATIENT

> T.S. is a 58-year-old man with hypertension and diabetes. He awoke with substernal chest pain that radiated to his left arm. When the pain did not improve he called the ambulance. T.S. lives outside of his community of 400 people and 40 miles from the nearest hospital. The volunteer ambulance crew arrived 20 minutes later and transported him to the hospital. The ambulance personnel placed T.S. on a monitor and administered oxygen and aspirin. No one in the ambulance crew that night was trained to place an IV and there was no equipment to do a 12-lead ECG. They administered three sprays of sublingual nitroglycerin in succession. They arrived at the emergency room 2 hours after his chest pain started.

The care of the rural emergency patient begins with the EMS. Rural EMS services are variable among communities. Providers are more likely to be volunteer emergency medical technicians (EMTs) whose training requirements vary from state to state. Compared with the paramedics and ambulance systems commonly found in urban settings, rural EMTs and EMSs often provide fewer services.[28] The relative lack of volume of trauma and emergent cardiac care plays a role in EMS service experience as well.

Distances traveled by EMS providers, both to reach patients and to transport them to the hospital, can be vast and are highly dependent on weather and road conditions. The time to transport plays a role in the poorer outcomes experienced by critically ill patients, and this holds especially true for patients who may benefit most from higher levels of care. Rural trauma victims are twice as likely to die as urban trauma victims.[29]

> When T.S. arrived at the emergency department (ED), he was met by the family physician on call for the ED, an RN, and the x-ray technician. His vitals were stable, but he continued to have chest pain. In the ED, an IV was started and morphine administered. A 12-lead ECG showed ST-segment elevation in the anterior leads. IV nitroglycerine was started.
>
> The closest tertiary care center with specialized cardiac care treatment was 50 miles away; 60 minutes by ground or 17 minutes by air. After evaluating the patient's condition, the services available at each hospital, and the weather forecast, the team decided to transport T.S. by air for emergency cardiac catheterization. Before he left, he was treated with anticoagulants in preparation for more definitive care.

The EDs in rural hospitals can be fully equipped and staffed for nearly every need or only intermittently staffed and providing limited services. Rural EDs are more likely to be staffed by family physicians, often local doctors who have practices in the community. Some have extensive training in emergency medicine and others less. The services offered in the rural ED depend as much on the local hospital capabilities as the provider. Imaging and laboratory services may not be available 24 hours per day.

Care of the rural emergency patient will continue to develop. Protocols for determining who should bypass smaller EDs and go directly to urban centers are beneficial and continue to evolve. Faster transport times aim to increase the care delivered in the first hour posttrauma, the "Golden Hour." Using techniques pioneered by the military, the "scoop and run" doctrine is useful in civilian settings where trauma is involved and may save lives in nontrauma settings as well. Improved technology in the field and in-hospital will also play a role. ECG transmission from ambulance to base facilities, telemedicine between rural hospitals and tertiary settings, and interhospital sharing of medical records also show promise.

CARE OF THE RURAL OBSTETRICAL PATIENT

> J.J. is a 26-year-old G2P1 Hispanic woman at 28 weeks of gestation. Two years ago, she delivered her first baby vaginally. She presented for early prenatal care but missed her scheduled appointment at 24 weeks because she and her family left town for work in a distant cherry orchard. She presents to clinic with ruptured membranes. The nurse escorts her across the street to the hospital for fetal monitoring. A bedside ultrasound reveals a transverse lie. She is assessed for safety of transport. Her cervix is 5 cm dilated.

The practice of maternity care and obstetrics can be one of the most professionally and personally satisfying aspects of rural medicine. A provider may be able to follow up a patient through her pregnancy, deliver her baby, and then care for the postpartum mother and the newborn. On the other hand, obstetrical practice in a rural community can be intimidating, as one may need to practice outside a typical comfort zone, and back up is sometimes scarce.

The rural pregnant patient is typically younger and poorer than her metropolitan counterpart. She is more often multiparous and a member of a minority group, and typically presents later to prenatal care, in part, due to transportation, distance to provider, and lack of insurance.[30] While maternity and child mortality in rural areas continue to decrease, rates remain higher than in the city.

The closing of rural hospitals or cessation of obstetrical services limits access to obstetrical care in rural areas. Obstetrical care in rural hospitals is discontinuous and unpredictable: a hospital may have no patients one day and several the next. This adds to the expense of staffing, which in turn may lead to more closure of services. Other factors that contribute to service limitations are liability, patient outmigration, lack of surgical services, and declining reimbursement.[31,32]

Provider issues limit access as well. The number of obstetricians practicing in rural areas is directly proportional to the population, and the provider of obstetrical care in rural areas is most often the community family physician. Unfortunately, the number of family physicians who provide obstetrical care is decreasing: from 35% in 1994 to only 19% in 2011.[33]

The emergence of obstetrical and rural fellowships in family medicine, rural residency tracks (RRTs) that encourage obstetrics, and the development of family medicine obstetrics board certification may improve the provider access issues. Currently, there are 31 family medicine obstetrical fellowships training between one and four fellows per year. There are 23 RRTs and an additional 12 in development. CNMs are also a part of the solution to access, as they are more likely to practice in poor and rural communities and provide safe and cost-effective care. These programs are on the rise as well.

While facility closure and a declining workforce threaten rural obstetrical care, innovations are improving outcomes with care close to home. Changes in call structures make the workload less rigorous for providers in rural areas. Technology solutions such as e-consults and live telemedicine are showing promise as well.

> The Antenatal and Neonatal Guidelines, Education and Learning System (ANGELS) links clinicians and patients in Arkansas with the University of Arkansas for Medical Sciences, where virtually all of the state's high-risk pregnancy services are located. The program facilitates real-time telehealth consultation among patients, their physicians, and medical center specialists through a statewide telemedicine network; develops and disseminates guidelines to foster the use of best practices by obstetric providers across the state through interactive teleconferencing; and facilitates appropriate referrals to the medical center for tertiary care through a 24/7 patient/provider call center.
>
> The patient is advanced in labor and too unstable to transfer to the nearest tertiary care center. She needs to be delivered via a cesarean section. The family physician asks the charge nurse to assemble the operating room (OR) team for a stat cesarean section and the ward clerk to call the neonatal transport team for the newborn. The physician last performed a cesarean section at 28-weeks' gestation when he was a resident; he calls and consults the remote obstetrician back-up. Together, they review the technical aspects of the surgery, and the obstetric consultant stands-by on the speakerphone in the OR as the cesarean begins. The surgery goes well and the newborn is delivered safely. The helicopter carrying the NICU team from the tertiary center arrives in time to stabilize the newborn and transport him. The mother recovers well and joins her baby at the tertiary care facility in 2 days.

This case illustrates both the technical skills and the teamwork required under difficult circumstances. Despite the challenges illustrated by this case, most obstetrical patients are healthy and have wonderful, uncomplicated deliveries, bringing great joy to families and the providers who serve them.

CARE OF THE RURAL SURGICAL PATIENT

> R.S. is a 66-year-old man with diabetes who presents to his primary care provider with fatigue. He is found to be anemic with a positive fecal occult blood test. He takes nonsteroidal anti-inflammatory drugs (NSAIDs) for his arthritis and smokes a half pack of cigarettes per day. His Primary care provider (PCP) refers him to the local general surgeon for endoscopy.

General surgery is important to the rural health-care ecosystem and the rural general surgeon is an endangered species. Patient outmigration to urban facilities, costs of

maintaining surgical services, changes in surgical residency training, liability, an aging workforce, decreased reimbursement, and lack of technical support (anesthesiology, radiology, pathology, etc.) are environmental factors leading to an overall decrease in the numbers of rural surgeons. Individual contributors include lifestyle issues related to long hours, increased call, and isolation.[34]

The absence of a general surgeon in a community can be devastating to the financial health of the local hospital and results in the loss of associated jobs and compromised hospital services including emergency and obstetrical care.[31] Historically, the local general practitioner or family doctor performed some general surgical procedures, including appendectomy, tonsillectomy, or herniorrhaphy. These cross-trained general practitioners have long since retired, leaving these services to the general surgeon. Many of the rural surgeons are now aging as well with limited opportunities for replacement. Graduates of surgical residencies are increasingly heading for subspecialty fellowships. Further exacerbating the decline of the rural general surgeon is that current surgical training programs are too narrow for the broad skill set needed for rural practice. In addition to the usual breast and abdominal procedures performed by general surgeons, the rural surgeon needs to be competent in upper and lower endoscopy, common gynecologic surgeries, cesarean section delivery, urologic procedures, and common orthopedic, vascular, and trauma procedures.[35]

> An upper endoscopy was normal but a colonoscopy revealed a 4-cm mass in the sigmoid colon. Biopsy results demonstrated adenocarcinoma. A subsequent computed tomographic scan demonstrated disease confined to the colon.

Rural general surgeons report significant job satisfaction in the areas of independence, access to outdoor activities, lack of turf battles with other physicians, and community and patient relationships.[36] Changes in surgical training and improved incentives for rural location are needed. Rural training tracks, like the program at Oregon Health Sciences University School of Medicine, help train graduates in the skills required for rural practice. The NHSC should include general surgery in its recruitment strategy. Medicare adjustments that improve reimbursement for care in rural areas might help. Recruitment alone, however, will be inadequate. Regional cooperation and coordination of services is needed to safeguard rural general surgical services.

> R.S. undergoes a left hemicolectomy at his community hospital. His family was able to visit every day as they did not need to travel to the regional center, and he was happy to be cared for by his neighbors who worked at the hospital.

CARE OF THE RURAL MENTAL HEALTH PATIENT

> T.T. is a 19-year-old woman cared for by an NP in an RHC since she was a child. She got pregnant at the age of 16 and lives with her mother who helps her care for her 3-year-old daughter. She has had periodic problems with methamphetamine but went through treatment last year and did well. Three months ago, her mother mentioned to her provider that T.T. had been emotionally labile and was sleeping all the time. She was diagnosed with depression and started on fluoxetine. She missed several follow-up appointments and 6 weeks later was found intoxicated at the local park after her mother had not seen her for 2 days. There were no dual diagnosis treatment beds available and the next open appointment with a mental health professional through the county mental health program is 1 month away. The NP adjusts her medications and plans to see her weekly in the office.

Rural patients are older, poorer, more likely to have chronic diseases, and more often uninsured compared with urban residents. All of these factors contribute to the high rates of mental illness, especially depression and substance abuse, seen in small communities.[37]

The front line for rural mental health care is the primary care provider. Patients with mental illness often present first to their regular provider who needs to be able to diagnose and, at minimum, initiate therapy when needed. Psychiatric training for primary care providers, including physicians, is variable, so is individual comfort levels in treating mental illness.[31]

For many patients, care from their primary care provider is sufficient. However, more complicated cases are problematic, and referral options are limited. Rural mental health services are commonly provided by social workers, psychologists, educators, and clergy; it is rare to have a psychiatrist available in town.

The availability of mental health services is only part of the challenge of delivering high-quality mental health care in rural communities. Rural communities lack anonymity and the risk, for example, of parking their readily identified car outside of a mental health facility can make care unacceptable to many patients. Many rural residents also come from traditions of self-reliance and exaggerated stigma related to mental illness and psychiatric care.

Some of the same qualities of rural living that create challenges for mental health care also offer opportunities. Close-knit communities with extended family can provide much needed comfort and reduce isolation for those suffering with mental illness. While many residents have an ethos of self-reliance, those living in small communities rally around neighbors, friends, and family in need. Religion plays a larger role in rural communities,

adding clergy to the team of potential mental health providers.

> One night T.T.'s mother called 911 after she found her lethargic at home carrying an empty bottle of Tylenol PM. Upon arrival at the ED, her acetaminophen level was high enough to require treatment. Once medically stable, she was involuntarily admitted to the state psychiatric facility 4 hours away, where she was diagnosed with bipolar disorder. She was started on a mood stabilizer by the treating psychiatrist. When no longer a threat to herself, she was discharged home with instructions to follow-up with her NP. She is followed up regularly by the NP and the local county mental health psychologist.

Since the 1960s, policymakers have been striving for mental health services to be better integrated into overall medical care. Nowhere is this more important than in rural communities. Incentives are needed for medical clinics and systems to hire mental health professionals and to site them side by side with the medical team. In the current environment, this is often financially impossible for many small offices. Building linkages with mental health services that allow for visiting mental health providers to work within clinics would be extremely valuable. Area health education centers that have typically focused on the primary care workforce are starting to attend to rural training for mental health providers as well.

Telemedicine offers tremendous promise in rural mental health. The Veterans Administration has been using this modality for psychiatric services for over 20 years. E-consults with rural providers as well as direct psychotherapy between patients and distant mental health professionals are used effectively in communities around the United States and internationally. The improvement of cellular technology holds promise for these modalities in many locations worldwide where traditional Internet services are not available.

CARE OF THE RURAL DENTAL PATIENT

> A 28-year-old man with tooth pain comes to see a dentist in a community of 4000 people. He has not seen a dentist since childhood and had tooth pain for several years but has not been able to afford care. He was seen in the local ED about a month ago and was noted to have an "abscessed tooth." The ED physician did a local injection for pain control and started him on antibiotics. He has diffuse decay with significant erosion among the right lower molars. He will need an extraction and possibly dentures.

There are proportionally fewer dentists and higher rates of dental caries in rural communities compared with urban towns. Over half of the rural counties in the United States are designated as Dental Health Professional Shortage Areas by the federal government.[38]

Rural residents are more likely to be without insurance coverage for dental care. Many Medicaid programs offer limited dental services, but only 25% of dentists in the United States accept Medicaid (ref). Medicaid patients are often more complex and might not be able to comply with instructions/prescriptions due to lack of education and other health issues. Although Medicaid patients are generally a more difficult, time-consuming, and expensive population to work with, dentists cite lack of reimbursement as the main reason they do not accept Medicaid.[38]

Despite the challenges, rural dentists report high professional satisfaction. Office space costs, employee salaries, and competition are all less in rural communities, while fees are generally comparable. Most rural dentists provide a full range of dental services and use modern equipment in quality facilities.

Remedies to fill the cavity of rural dentistry include multilevel approaches from public health to the dentist's chair. Increasing water fluoridation would be the most cost-effective solution, but rural communities rely on well water and smaller water systems that are less easily converted.[39] Furthermore, many rural residents are resistant to water fluoridation. Recruiting dental students from rural areas and developing educational partnerships to provide rural experiences for dental students could address some workforce needs. Following the lead of countries from Nepal to New Zealand, training midlevel dental practitioners to provide routine preventative care, fillings and simple extractions, has expanded access to dental care to 35,000 patients in remote rural areas of Alaska.

CONCLUSION

The intimacy of caring for rural patients and their communities is among the most venerable and satisfying pillars of medicine. Caring for multiple generations of the same family, practicing to the widest scope of training, and having a direct and meaningful impact on the community are the norm rather than the exception for many rural providers. But now more than ever, rural communities are faced with numerous challenges that threaten access to quality health care. The ongoing success and improvement of services in small towns will continue to evolve and rely on regional and national government initiatives as well as the long-term partnership between the community and health-care professionals, clinics, and hospitals.

Important Elements of Social History for Rural Patients

- How far will the patient need to travel to receive care, including subspecialty care, diagnostic testing, and treatment?
- Does patient have adequate transportation?
- Is there a pharmacy in town? How much travel is needed to get medications or can they be sent by mail? (Clinics may need to be able to provide several days of medications if needed urgently.)
- Does patient have a reliable phone?
- Does patient have a satisfactory living situation?
- Is the patient isolated or connected to family or community?
- Does patient have occupational risks? Recreational risks?
- What resources might the patient need that are available in the community?
- What resources might patient need that are outside of the community?
- Are community resources acceptable to the patient?
  - Is the community so small that privacy concerns might increase patient's reluctance to buy from the local pharmacy or access local resources?

- Rural populations are vulnerable.
- There are multiple aspects of rural living that contribute to health in rural populations.
- Provider maldistribution is a significant barrier achieving health equity in rural areas.
- Health-care systems and government regulations play an important role in access to care in rural communities.
- Rural patients present unique challenges and opportunities to health-care providers.

DISCUSSION QUESTIONS

1. Among the benefits of rural practice, which do you think might be most relevant to health-care professional students and trainees as they are deciding on future careers?
2. Discuss the benefits of interprofessional training for rural health-care providers.
3. What challenges and opportunities can you identify to using the chronic illness care model and population-based interventions in rural practice?

RESOURCES

National Rural Health Association—The NRHA provides leadership on rural issues through advocacy, communications, education, and research. http://www.ruralhealthweb.org/.

U.S. Department of Agriculture Amber Waves—Amber waves is a newsletter style publication highlighting the economics of rural living. http://www.ers.usda.gov/amber-waves#.U2KIZse5Cxo.

World Health Organization—WHO is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends. http://www.who.int/about/en/.

Federal Office of Rural Health Policy. Provides detailed information on all aspects of rural health, federal and state programs, grants and research. http://hrsa.gov/ruralhealth.

National Association of Community Health Centers. http://www.nachc.org.

National Association of Rural Health Clinics. http://www.narhc.org.

RUPRI—Rural Policy Research Institute. Excellent site for all policy issues and information on current research. http://www.rupri.org.

Handbook of Rural Health Ethics: A Practical Guide for Professionals. Dartmouth Family and Community Medicine Department. http://geiselmed.dartmouth.edu/cfm/resources/ethics/.

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Chapter 31

Providing Care to Patients Who Speak Limited English

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Objectives

- Highlight the clinical consequences of language barriers.
- Describe evidence for professional interpreters and for bilingual clinicians.
- Describe the limited-English–speaking population in the United States.
- Review policies pertaining to linguistic access in health care in the United States.
- Describe institutional responses to overcome language barriers.
- Summarize strategies to address language barriers in clinical practice.

INTRODUCTION

Health-care providers are better educated and more scientific than ever before, but they have a great failing: providers sometimes do not communicate effectively with their patients or with the patient's family.[1]

The current health-care system offers some of the most technologically advanced medicine in the world. At the same time, millions of people in the United States, and increasingly throughout the world, have limited access to the most basic feature of good medical care: adequate communication.[2] Effective patient–provider communication is essential to providing good medical care. Taking an accurate history is fundamental to being a diagnostician; the history is the key to the final diagnosis in 56–82% of cases.[3] Moreover, the quality of communication also affects patient and physician satisfaction, patient adherence, and clinical outcomes.[4] Unfortunately, in the United States, many people are unable to reap the benefits of effective communication because they cannot speak English well.

The ability to navigate a health-care system depends in large part on the capacity to speak and understand the official language. Language barriers can hinder care from simple communications such as calling for an appointment, to emergent situations such as explaining symptoms to an ambulance paramedic, to more nuanced exchanges such as discussing treatment risks and benefits with a doctor. The consequences can be dire.

This chapter is designed to help readers understand the impact of language barriers on both patients and clinicians, and provide guidance to overcome them. Although many of the ideas in this chapter pertain to language barriers in any health-care setting, we will focus on language barriers in the United States. We begin with an overview of language barriers in health care, including who faces these barriers, how language barriers affect health care, and current policies regarding linguistic access in US health-care settings. We conclude with practical suggestions clinicians may draw from to better care for limited-English–speaking patients.

LIMITED ENGLISH PROFICIENCY AND HEALTH CARE

Miguel Hernandez immigrated to the United States 5 years ago. Despite working long days, he takes English as a second language (ESL) classes in the evenings and on weekends.

> He is able to say and understand basic things in English, but this becomes more difficult when he is under stress. When he presents to the emergency department with an episode of recurrent nephrolithiasis, he does not know enough English to share his past medical history, alert the nurse of his codeine allergy, or describe his symptoms in detail to his doctor.

Limited English proficiency (LEP) refers to patients such as Mr. Hernandez who cannot speak, read, write, or understand the English language at a level that permits them to interact effectively with health-care providers. Since 1980, the US census has used a set of standardized questions to ask about language ability. Anyone who reports speaking English less than "very well" (i.e., "well," "not well," or "not at all") is considered to be LEP by this population criterion.[5]

In clinical settings, a two-step process most reliably ascertains LEP status[6]:

1. Step 1: Ask the patient to report their proficiency in English. For those who report that they speak English less than "very well."
2. Step 2: Ask the patient to report their preferred language for health care.

Guidelines, including from the Institute of Medicine (IOM) (2009), emphasize this two-step approach to the collection of language data rather than asking patients simply if they need an interpreter—a question that can be misunderstood, especially if an English-speaking family member accompanies the patient. If patients are asked only about their language preference, about 20% may be misclassified as LEP as they prefer their native language for health care yet speak English "very well."[7] This misclassification may obscure LEP-associated health-care disparities and confuse quality improvement efforts.

In the case of Miguel Hernandez, basic command of English that may suffice at the grocery store or post office may be inadequate to communicate in health-care settings. Given that communication is bidirectional, another important gauge of a patient's LEP status is whether or not the clinician believes the patient is capable of expressing concerns and understanding recommendations.

THE LIMITED-ENGLISH–SPEAKING POPULATION IN THE UNITED STATES: LARGE, DIVERSE, AND GROWING

According to the US census, the number of Americans aged 5 years or older who spoke a language other than English at home grew from 23.1 million in 1980 to 60.5 million in 2011. The percentage who were considered LEP experienced similar growth,[5] increasing from 4.8% in 1980 to 8.7% in 2011.

More than 380 different languages are spoken across the United States.[5] Although Spanish accounts for about 62% of people who speak a language other than English at home, because of changes in immigration patterns, other languages are increasingly likely to be encountered (Figure 31-1). Between 1980 and 2010, Vietnamese speakers experienced the largest percent growth at 559%. During the same time period, four languages that had less than 200,000 speakers in 1980 more than doubled. These languages were Vietnamese, Russian, Persian, and Armenian.[5]

Among these various language groups, the proportion of people who are LEP varies considerably. For example, more than 50% of Korean, Chinese, and Vietnamese speakers and 46% of Spanish speakers are LEP, whereas 20% or less of French or German speakers are LEP.[5] The greatest concentrations of LEP residents are in California, where according to the 2010 US Census Bureau American Community Survey, nearly one in every five people is considered LEP.[8] Other states with high percentages of LEP residents include Texas (14.4%), New York (13.5%), New Jersey (12.5%), Nevada (12.3%), Florida (11.9%), Hawaii (11.8%), and Arizona (9.9%).[8] However, the greatest increase in LEP populations has been in southeastern and western states such as Georgia, North Carolina, and Nevada, all of which experienced more than 300% growth[8] between 1990 and 2010. Given the relative lack of established language access services in these "emerging" LEP communities, clinicians working in these high-growth states may face particular challenges in caring for their LEP patients.

LEP individuals are more likely than English-speaking members of the same ethnic group to be older, less educated, low income, and to have been in the United States for a shorter period of time.[9] Given these demographic patterns, clinicians caring for LEP patients often encounter concurrent challenges of poverty, lack of insurance, and low functional health literacy and cross-cultural communication. However, although these issues are often intermeshed, they are also distinct, and require sensitivity to the individual patient's background. For example, a patient may speak little English, but be highly educated, literate in her or his native language, and accustomed to and accepting of western biomedical concepts.

LANGUAGE BARRIERS HAVE CLINICAL CONSEQUENCES

> Ha Lang, an elderly Cantonese-speaking woman, is hospitalized because she took too much warfarin. Late at night, she gets up to go to the bathroom. A nurse on duty stops her and tries to get her back into bed. When Mrs. Lang persists in wanting to go to the bathroom, the nurse thinks she is agitated. Instead of calling for an interpreter, the nurse has Mrs. Lang put in arm restraints and gives her a sedative (Box 31-1).

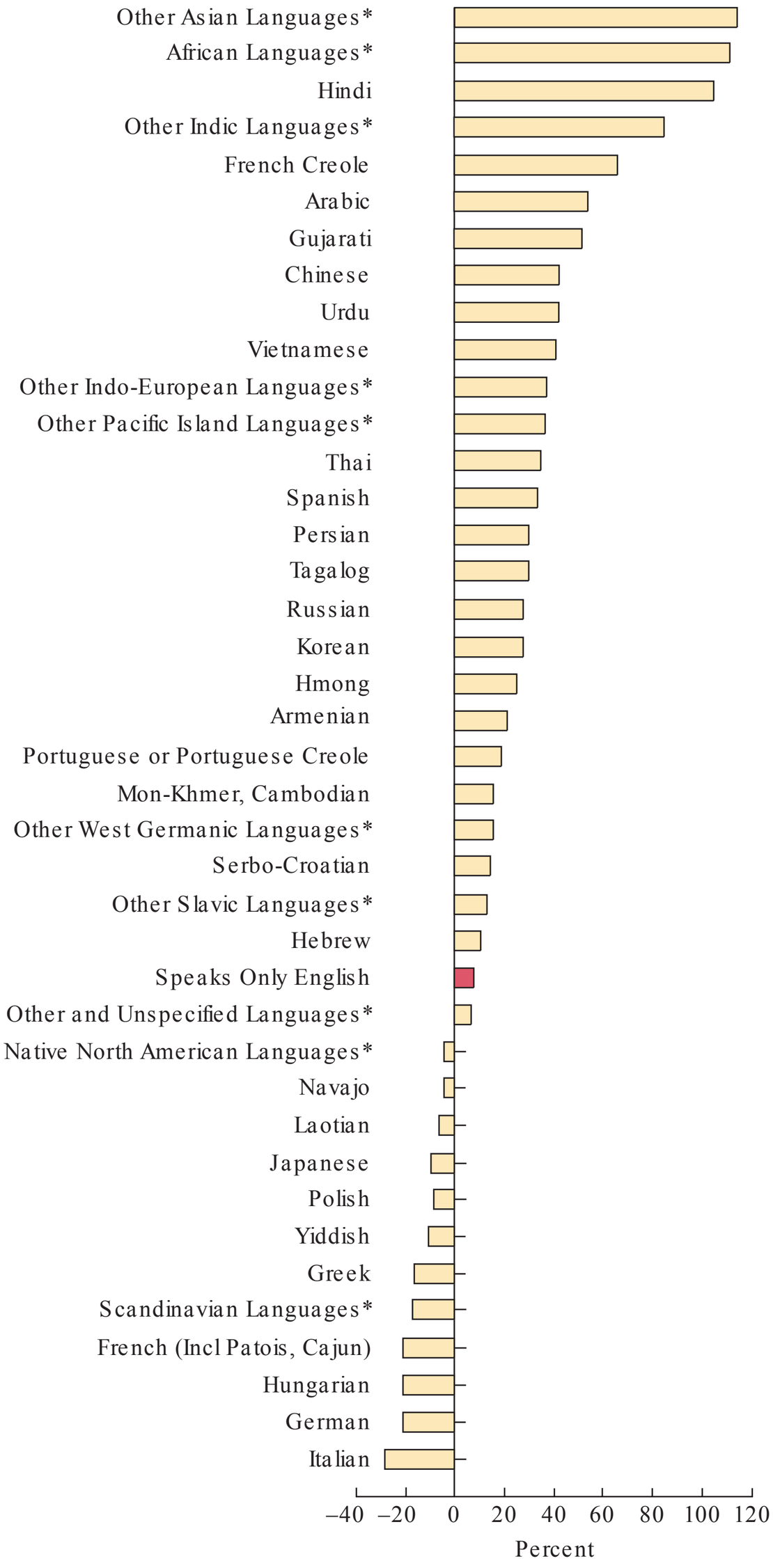


Figure 31-1. Percentage change in language spoken at home: 2000–2011. The figure depicts the changes in language spoken at home for individuals 5 years of age or older over a 10-year span. (Adapted from Ryan C. Language Use in the United States 2011 American Community Survey Reports. Washington, DC: US Census Bureau, 2013. Available at https://www.census.gov/prod/2013pubs/acs-22.pdf. Source: U.S. Census Bureau, Census 2000 and 2011 American Community Survey.)

IMPACT ON ACCESS TO CARE

In studies with a wide range of LEP health consumers, language barriers are often reported as being one of the most important, if not the most important, barrier to accessing care.[10-12] When compared with English speakers, limited-English–speaking patients are less likely to be insured[13,14] or know about public health insurance programs,[15] and their children are less likely to have a usual source of care.[16] Limited-English–speaking patients are also less likely to receive physician visits,[17,18] dental care,[19]

Box 31-1. Common Pitfalls in Health Care for Limited-English–Speaking Patients

- Language is one of the most significant barriers to health care for immigrants in the United States.
- Limited-English–speaking patients understand less of what occurs during health-care visits than English speakers.
- Limited-English–speaking patients tend to receive lower quality of care than those who speak English very well.
- Using interpreters has been shown to improve understanding and quality of health care, though a comprehension gap remains when compared with care provided by bilingual clinicians.
- Despite growing numbers of limited-English–speaking patients and legal mandates requiring provision of interpreter services, these services are often lacking or inadequate.

eye examinations,[19] mental health visits,[17] or referrals from the emergency department after discharge.[20]

IMPACT ON PROVIDER–PATIENT RELATIONSHIP

Even when limited-English–speaking patients are able to access care, they have been found to be less likely to understand what transpires in the clinical encounter, from basic medical terminology[21] to discharge diagnoses,[22] to prescribed medications.[23,24] In a telling study that sought to evaluate two types of state-of-the-art medical interpretation, patients presenting to a New York City emergency department were nearly twice as likely to report comprehension of diagnosis if their physician spoke their language than if the encounter was conducted via either of the excellent interpreting systems.[25]

Patients with language barriers are less likely than patients who do not have language barriers to engage in active exchanges with their providers[26] or feel as if they played an active part in decision making.[27] Perhaps as a result, they are less likely to be satisfied with their medical encounters,[27–30] their individual providers,[31,32] and the institutions that provide care.[23,29]

IMPACT ON QUALITY OF CARE

In nearly every clinical setting that has been examined, language barriers appear to result in lower-quality care. Limited-English–speaking patients are less likely to receive recommended preventive care such as mammograms,[17] pap smears,[33,34] colon cancer screenings,[35] and influenza vaccinations.[17,35] In psychiatric settings, LEP status has been associated with inadequate evaluation and diagnosis.[36,37] In palliative care settings, LEP patients are less likely to have adequate symptom control,[38] and in obstetrical settings, they are at higher risk of experiencing a nonsterile delivery.[39] Once LEP patients present to the emergency department, they receive more diagnostic tests,[40] are more likely to be hospitalized,[14,41] and, once hospitalized, tend to have a longer length of stay[42] than English-speaking patients with similar conditions. Patients with language barriers are less likely to receive informed consent for invasive procedures, despite the clear violation of law.[43]

PATIENTS HAVE A LEGAL RIGHT TO LANGUAGE ACCESS IN HEALTH CARE

There are a number of federal and state laws that give limited-English–speaking patients a legal right to language assistance services in health-care settings. On the federal level, Title VI of the 1964 Civil Rights Act has been interpreted by the US Department of Health and Human Services (HHS) to mean that any health-care organization that receives federal money—for example, Medicare or Medicaid payments—is obligated to ensure linguistic access for its LEP patients.[44] More recently, HHS' Office for Civil Rights has issued guidelines for health-care providers to follow in determining what type and extent of language assistance services to offer.[45] The Centers for Medicare and Medicaid Services (CMS) also has issued regulations that require Medicaid health plans to make interpreter services available to their enrollees free of charge.[46] The Affordable Care Act (ACA) explicitly requires insurers and health-care institutions to provide written translation and interpreting services for LEP patients of qualifying language groups.[47] (For a quick primer on the ACA and language access services, see http://www.languagescientific.com/language-services-blog/affordable-care-act-language-service-requirements.html.)

Despite legal mandates, limited-English–speaking patients continue to face barriers when they attempt to access health services. This results, in part, from incomplete coverage and inconsistent enforcement of federal and state laws, limited availability of trained health-care interpreters; lack of adequate financing for language access services; and clinician and patient willingness to just "get by."[48] In the face of these challenges, it is critical that health-care providers understand how they can optimize their communication with LEP patients.

BRIDGING THE LANGUAGE BARRIER

> Michelle Nguyen was admitted from the emergency department for management of preterm labor. She was crying and distraught. Because she spoke only Vietnamese, her husband interpreted for her, reporting that she was frightened as this was her first pregnancy. A few weeks later, she was

seen for follow-up care by a nurse practitioner; this time, Mrs. Nguyen's 12-year-old daughter, in tears, was able to convey that the reason her mother had come to the emergency department was that her husband had assaulted her, causing the preterm labor.

WHO IS THE MEDICAL INTERPRETER?

The distinction between ad hoc untrained interpreters and trained medical interpreters is critical. Ad hoc interpreters have been shown to make frequent errors, including omissions, paraphrasing, use of incorrect words, substitutions, additions, and inappropriately providing their own personal views.[49–51] Family members and friends are particularly unsuitable when domestic violence or a potentially embarrassing symptom needs to be evaluated.[52] Minor children should never be used as medical interpreters, because it often places them in uncomfortable and frightening positions, and distorts their proper role within a family.

In contrast, professional medical interpreters are expected to have fluency in both English and a second language, have a command of medical terminology, understand basic medical concepts, have the necessary skills to manage a three-way conversation, be committed to interpreting accurately and completely without adding their own opinion, and abide by a code of ethics that respects patient confidentiality. Frequently they are trained in how to deal with difficult situations, such as cases of domestic violence, as well.

Each type of medical interpreter should be carefully weighed before deciding how best to proceed (Table 31-1). The following sections provide guidance on when and how to use bilingual skills, professional medical interpreters, and ad hoc interpreters. Clinicians also should check their organization's policy about the use of interpreters. Some organizations require the exclusive use of staff interpreters, and prohibit the use of ad hoc interpreters.

USING YOUR OWN BILINGUAL SKILLS

Ismelda Garcia speaks a little English, and her doctor knows a few words in Spanish. She leaves her doctor's office with a new prescription for "pression alta" (high blood pressure), which she was instructed to "take once cada dia" (each day). When she ends up in the emergency room a day later feeling lightheaded, the emergency department nurse brings in the hospital's Spanish interpreter to take a history. It turns out that the word written as "once" in English means "11" in Spanish.

Not surprisingly, when they can, LEP patients choose clinicians who can speak their language.[9] Language concordance between physicians and patients has been shown to increase patient satisfaction[53] and recall, self-reported health status,[54] ratings of care,[55] and possible medication

Table 31-1. Types of Medical Interpreters

Interpreter Type	Advantages	Disadvantages
No interpreter (e.g., bilingual clinician)	• Direct communication between patient and clinician is quicker and allows for better rapport • No concerns about confidentiality, as third party is not involved in the encounter • Patients appreciate their clinicians' attempts to converse in their language	• There are a limited number of truly bilingual clinicians • Risk for miscommunication and misdiagnosis if clinicians overestimate their language skills
Bilingual staff (e.g., secretary, medical assistant, custodial staff)	• Convenient • No additional salary costs • Patients are often comfortable with health-care staff	• Disrupted patient flow and inefficiencies, as staff cannot interpret and perform other duties simultaneously • Risk for inaccurate interpretation if staff do not have sufficient bilingual skills or know medical terminology
Professional interpreter (trained and tested)	• Less likely to make interpreting errors • Trained in ethics • Patients may be more likely to share sensitive information with a professional	• May require wait, particularly if there is institutional imbalance of supply and demand • Salary costs of hiring professional interpreters • Patients may not be comfortable with having a stranger involved in their communication
Ad hoc interpreter (e.g., patient's family member or friend)	• Convenient • Free for provider and institution • Patients may prefer to communicate through friends or family members	• Usually have inadequate bilingual language and interpreting skills • High rates of errors and omissions • Communication may be modified to suit the interpreter's agenda • Loss of confidentiality • Use of minor children is unethical

adherence.[56] Language concordance has also been shown to be associated with better glycemic control for patients with diabetes, despite a setting with ready access to professional interpreters.[57]

Given these benefits, a variety of programs have been developed to teach medical students and residents medical Spanish, ranging from 20 hours of basic language instruction to intensive, longitudinal immersion experiences.[58] Patients appreciate their clinicians' efforts to learn their language, and respond with increased levels of trust. At the same time, it is important for clinicians to have an accurate sense of their own language proficiency, and be aware of their own limitations. Most medical student programs do not test competence in interpretation.[59] As in the preceding vignette, false fluency can be confusing or lead to significant miscommunication with clinical consequences.[50]

Clinicians can gauge whether they need an interpreter by considering (a) how they learned the language and in what context, (b) how often they need to search for alternate ways to express themselves or ask patients to repeat themselves, and (c) the content and emotional tenor of the clinical exchange (Box 31-2). An additional consideration, particularly for clinicians who grew up speaking another language at home, is familiarity with medical terminology, such as appendix, thyroid, or computed tomography scan. Clinicians should keep in mind that we are prone to overestimating our skills. Formal language testing is increasingly recommended as a way to provide quality control on clinician language skills.[59]

The level of proficiency required may vary depending on the content and emotional tenor of the clinical exchange. A clinician with moderate language skills may be able to successfully diagnose and treat an otherwise healthy 27-year-old with a sprained ankle, but may need to call on a trained medical interpreter to evaluate an episode of syncope in a 78-year-old with multiple medical conditions. If at all uncertain, the clinician should ask for a professional interpreter. Furthermore, clinicians should not be reluctant to refer to a fully bilingual colleague when one is available and willing: the literature on interpreter-mediated communication indicates that bilingual clinicians are far preferable to patients over even professional interpreters, as they improve comprehension, trust, and patient satisfaction.[32]

Box 31-2. Assessing Your Bilingual Skills

For clinicians who use their own bilingual language skills in the patient encounter, doing a self-assessment is critical. Is the clinician able to do the following?

- Formulate questions easily and effectively, without frequently being stuck on vocabulary.
- Ask questions in a different way if not understood.
- Understand the response, including regional variations, nuance, and connotation.
- Explain relevant health-care concepts.
- Negotiate and agree on a course of action.
- Inspire trust by communicating competence.

Source: Adapted from Roat.[60]

WORKING WITH PROFESSIONAL MEDICAL INTERPRETERS

> A day in the life of an interpreter: "Before going into the room, the physician expresses to me his concern about whether the health problems claimed by this woman are real or imagined. She has been in the clinic three times before, each time with different vague and diffuse complaints, none of which makes medical sense. As we learn, the poor woman has a fistula in her rectum. In her previous visits, she could not bring herself to reveal her symptoms in the presence of … her son as he interprets for her. She tells me that she has been so embarrassed about her condition that she has invented other symptoms to justify her visits to the physicians. She confesses that she has been eager to have a hospital staff interpreter from the first visit, but her hope had not materialized until now."[52]

Professional medical interpreters are beneficial in a number of clinical arenas. They make fewer errors of clinical consequence,[50] improve the patient centeredness of encounters, reduce disparities in the use of preventive health services,[35] decrease the use and costs of emergency department testing,[61] and are associated with higher-quality care,[62] as well as enhanced physician and patient satisfaction with the encounter.[53,63]

A clinician can work with an interpreter who is either physically in the same room (a face-to-face or in-person interpreter) or is located outside the examination room, most commonly, a telephone interpreter, though video-mediated interpretation is increasingly common. Although both clinicians and patients prefer working with an in-person or video-mediated professional interpreter,[64] many institutions may only have easy access to professional telephone interpreters. There are important considerations in deciding whether using a telephone interpreter will be sufficient for your needs (Table 31-2). Similar skills are used in working with both types of trained interpreters (see "Core Competency").

A caveat: the field of medical interpreting is relatively new in the United States. There are currently two national interpreter organizations that set professional standards an issue certificates (http://www.certifiedmedicalinterpreters.org/ and http://www.cchicertification.org/). All professional interpreters should be certified through one of the two organizations or have equivalent proof of competence.[65]

Table 31-2. Choosing an In-Person or Telephonic Interpreter

In-Person	Telephonic
When delivering bad news	When in-person not available
With patients with significant hearing loss	With relatively straightforward encounters
With patients from cultures unaccustomed to using telephone	When access to an interpreter is required immediately
For conversations with more than one person, e.g., family conference	When privacy and confidentiality is critical, particularly in small communities[a]
For psychiatric encounters, psychosis is present or communication of effect critical	When health of patient mandates minimal exposure, e.g., immunocompromised patients.

Source: Adapted from Roat C. Addressing Language Access Issues in Your Practice: A Toolkit for Physicians and their Staff Members. San Francisco: California Academy of Family Physicians, 2005.
[a]In small communities, interpreters and patients often know each other. Using an interpreter from a telephonic interpreter service almost always guarantees patient privacy.

WORKING WITH AD HOC INTERPRETERS

Sometimes a trained interpreter may not be available. Although the level of communication may be limited by the ad hoc interpreter's skills, observing certain guidelines (see "Core Competency") can improve the quality of the interpretation.[60] It is important to consider the import, sensitivity, and urgency of communication when determining what kind of interpreter you use. If it is an emergency situation and there are no trained in-person interpreters immediately available, you should use an ad hoc interpreter rather than waiting for a professional interpreter. With a sensitive subject, such as exposure to sexually transmitted diseases, using a trained interpreter rather than a family member or friend is more likely to elicit the critical information you need. Except in life-threatening situations, young children should never be used as interpreters.[66]

CONCLUSION

The recent increase in ethnic, cultural, and linguistic diversity in the United States and worldwide has been accompanied by a great need for language access services in health-care settings. A growing body of research shows that language barriers result in decreased patient access, satisfaction, comprehension, and adherence, as well as an increased risk of errors, inappropriate utilization, and higher costs. Access to bilingual providers or competent interpreter services can help address these risks. Unfortunately, many health-care organizations have not yet developed the internal capacity or infrastructure to provide coordinated, consistent language access for their patients. Clinicians must learn how to care for LEP patients within these limitations by recognizing the boundaries of personal clinical language skills, learning how to work with both trained and untrained interpreters, and knowing when to refer to a bilingual clinician.

- Adequate interpretation is essential to the delivery of care to patients with limited English abilities.
- Learning to work with different types of interpreters is an essential clinical skill.
- Bilingual clinicians should learn to evaluate their language abilities and the clinical situation before forgoing the use of a trained interpreter. Increasing numbers of organization are requiring testing of clinician language skills. This requirement may advance the care of LEP patients.
- Use of professional interpreters improves quality of care.
- Except in life-threatening emergencies, young children should never be used as interpreters.

Working with Trained and Ad Hoc Interpreters

Setting	Ad Hoc Interpreter	Trained Interpreter
Before beginning the clinical encounter	1. Assess the ad hoc interpreter's English skills and familiarity with medical concepts. 2. Be attuned to the interpreter's limitations in the non-English language, particularly with younger people whose primary language is English. 3. Explain to the untrained interpreter that she or he will be your ears and your voice.	1. Briefly explain the purpose of the encounter to the interpreter. For example, "Mr. Ukomadu is here for routine follow-up of hypertension and diabetes," or "Mrs. Saleb is here to discuss her biopsy results; she has cancer." 2. Remember the interpreter is not a clinician. It is not appropriate for the clinician to hand the interpreter an informed consent form for the patient to sign and then leave the room. The patient may have questions that the interpreter cannot answer.

Setting	Ad Hoc Interpreter	Trained Interpreter
	4. Ask him or her to interpret accurately and completely, avoid paraphrasing or answering for the patient, and let you know if she or he needs you to slow down, explain, or repeat something. 5. If the interpreter is a family member or friend, it can be helpful to let him or her know that you welcome the interpreter's opinion, but he or she needs to differentiate between his or her personal opinion and the patient's. 6. Give the untrained interpreter permission to stop and let you know if she or he is having difficulty interpreting something you or the patient is saying. Otherwise, out of fear or embarrassment, she or he may gloss over difficulties and contribute to miscommunication.	3. Consider the appropriateness of the interpreter. There may be historical animosities between ethnic groups that may make an interpreter unacceptable to a given patient, or regional dialects that make communication difficult. On rare occasions involving highly sensitive matters, telephone interpretation—which increases patient anonymity—may be preferred. 4. For some sensitive issues, patients may feel strongly about having an interpreter of the same gender.
During the clinical encounter	1. Speak slowly and clearly, pausing between each sentence. 2. Use simply constructed sentences and plain English; avoid medical terminology and professional jargon (e.g., "workup"). 3. Speak to and look at the patient. 4. Be attuned to interpersonal dynamics between the patient and interpreter, particularly if the interpreter is a family member or friend.	1. Look at and talk to your patient, not the interpreter or telephone. For example, ask Mr. Rodriguez, "How are you doing?" rather than asking the interpreter, "How is he doing?" 2. Ask one question at a time. 3. Speak at an even pace, in relatively short segments. Pause regularly to allow the interpreter time to interpret.

Setting	Ad Hoc Interpreter	Trained Interpreter
	5. Check in frequently with the patient using the "teach back" method. For example, after conveying a new diagnosis of diabetes, ask the patient to explain what she or he understands. 6. If the interpreter and patient get into an exchange that is not being interpreted, gently remind the interpreter that you need to know everything that is being said. Similarly, if the interpreter answers for the patient, remind the interpreter that you need her/him to interpret, even if s/he knows the answer to the question. 7. Elicit the patient's viewpoint. Remember that interpreted interaction can be less patient centered and ask open-ended questions and direct elicitation questions (what do you think about starting this medication?) to make sure you have heard the patient's concerns and point of view.	4. Avoid interrupting the interpretation. Many concepts have no linguistic or cultural equivalent in the patient's language, so the interpreter may need extra time to explain. 5. Pay attention to nonverbal cues that may indicate a need for further clarification or discussion. 6. Assess patient understanding using "teach back" or similar methods. 7. Elicit the patient's viewpoint. Remember that interpreted interaction can be less patient centered and ask open-ended questions and direct elicitation questions (what do you think about starting this medication?) to make sure you have heard the patient's concerns and point of view.

DISCUSSION QUESTIONS

1. How does communication, or miscommunication, affect quality of care? (Try to elicit and synthesize both research evidence and personal experiences.)
2. Do you speak a language other than English? If yes, what do you think about your ability to adequately communicate with patients in that language after reading this chapter?
3. Have you ever used an ad hoc interpreter? What did it feel like? What could you have done to improve the patient encounter?

4. Does your institution provide professional interpreters (in-person or by telephone)? If yes, how are interactions with professional interpreters different from those with ad hoc interpreters?
5. Have you ever referred a patient to a colleague for a "language concordant consultation"? In what scenarios might you do so?

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Chapter 32

The Care of Lesbian, Gay, Bisexual, and Transgender Patients

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Objectives

- Understand the social and medical context in which lesbian, gay, bisexual, and transgender (LGBT) patients seek health care.
- Describe major medical and psychosocial concerns in LGBT patients.
- Summarize strategies to promote culturally appropriate care for LGBT patients.

Dr. Nguyen is in the middle of her busy family practice clinic. She enters the room to see her new patient "Mr. John S." and is puzzled to see the notation "due for Pap" among the reminder notations. The patient is male appearing and appears quite apprehensive and angry. Dr. Good asks what can she do to help and Mr. S explains with some hesitation that he is a transgender man and has female anatomy and therefore requires a Pap smear. His previous medical provider was uncomfortable with this and suggested that Mr. S. see a "gay friendly" doctor. Dr. Good was listed on a Web site so Mr. S made an appointment but is now upset because the front desk staff had loudly stated, "there must be a mistake, it says here you need a Pap smear" and then began to stare at Mr. S and laugh nervously.

INTRODUCTION

Lesbian, gay, bisexual, and transgender (LGBT) Americans and Western Europeans now experience a degree of equality, visibility, and support that was unimaginable in the past. LGBT people are much more visible in the media, workplaces, schools, government, places of worship, and a host of other settings. As LGBT people have gained visibility, equality, and support throughout our society, they have received increasing attention in health care and health education.

Health-care providers are likelier than ever before to be personally acquainted with someone LGBT and to have a general familiarity with LGBT experiences and concerns. Consequently, health-care providers must be equipped to offer truly welcoming, knowledgeable, and sensitive care to LGBT patients, who face particular challenges in health care. This chapter describes the health-care concerns of LGBT patients and explains how health professionals can best address them, creating optimal medical outcomes and building relationships of comfort and trust.

"LGBT" TERMINOLOGY

Optimal care for LGBT patients begins with an understanding of those to whom the "LGBT" acronym refers. This chapter uses "lesbian" to refer to women primarily attracted to other women; "gay" to refer to men primarily attracted to other men; "bisexual" to refer to those attracted to both men and women; and "transgender" to refer to two groups: those who identify with and transition to a gender other than the one assigned to them at birth, and those who express gender differently from prevailing norms in our society. In other words, the terms "lesbian," "gay," and "bisexual" refer to sexual orientation, while "transgender" refers to gender identity or gender expression. A patient who is transgender could have any

sexual orientation: heterosexual, lesbian, gay, or bisexual. For this reason, laws and policies prohibiting discrimination against LGBT people are often worded to forbid discrimination related to both sexual orientation and gender identity and expression.

CREATING A WELCOMING ENVIRONMENT FOR LGBT PATIENTS

While estimates of the number of LGBT Americans vary for a host of reasons, it is entirely safe to say that LGBT people live in every area of the country and are well represented in every subgroup of Americans (e.g., ethnic/racial minorities, religious faiths, income classes, rural/suburban/urban dwellers).[1] Health-care providers may not know which or how many of their patients are LGBT, but all will treat LGBT people in the course of their careers, regardless of their location or professional role.

It is critical for providers to remember that any patient could be LGBT, whether or not she or he matches stereotypes of LGBT people. For example, a male patient who refers to himself as "married" could be wedded to another man. A woman who resembles a provider's grandmother could well say that she is a lesbian. A young male athlete, who has previously mentioned only sexual relationships with women, may say that he has recently become sexually active with men. And a woman whose husband has accompanied her to take notes on future treatment may indicate that she was "assigned male" at birth. In all of these situations, it is critical not only that health care be unaffected by learning a patient's LGBT status but also that provider–patient rapport remains strong after LGBT status becomes known. In fact, the moment in which a patient's LGBT status becomes known to a health professional is a critical and sensitive one. Even with much progress toward LGBT equality nationwide, it often is not easy for LGBT people to be "out," particularly in settings like health care, where they may feel especially vulnerable.

When a patient does choose to come out, or when a health-care provider otherwise becomes aware that a patient is LGBT, it is important for the provider to signal that care will not be negatively affected. A warm smile or nod, a friendly greeting to a newly introduced same-sex spouse or partner, or a response such as "Thank you for sharing that—I know it's not always easy" can greatly ease LGBT patients' worries about how they will be treated. In fact, a sense that their provider is "friendly" can do much to encourage them to pursue needed care and to help create the trust and rapport that improve health outcomes.

DISCRIMINATION CONCERNS

Despite much progress for LGBT Americans, they continue to be concerned about discrimination in health-care and other settings. This is particularly true for transgender individuals, who have gained visibility and discrimination protection much more recently and on a more limited basis than LGB people. For example, one national survey of LGBT people about their health-care perceptions and experiences[2] found that 28% of LGB, 35% of HIV+, and 73% of transgender respondents believed they would be treated differently in health care because of their sexual or gender identity. In addition, significant percentages of respondents reported having experienced discrimination in health care because of their LGBT status, including verbal harshness, physical roughness on the part of some health-care providers, and aversion to physical contact on the part of others. Another national survey revealed that these phenomena are particularly common for transgender patients, who may additionally experience unduly long waits for care, confidentiality violations, "gawking," biased comments, challenges to bathroom use, and interviews and exams unrelated to their actual complaints.[3]

Behavior such as this in health-care settings may run afoul of state laws that forbid discrimination related to sexual orientation and gender identity and expression. In addition, the Joint Commission in the United States calls on accredited hospitals to prohibit such discrimination,[4] and growing numbers of health-care facilities are voluntarily instituting policies that ban discrimination and embracing practices that promote LGBT patient-centered care and extend a welcome to LGBT patients.[5] The policies and practices recommended in the following table can do much to welcome LGBT patients, assure them of equity and inclusion, and build comfort and trust (Box 32-1).

MEDICAL CARE FOR LGBT PATIENTS

Lesbians comprise between 1% and 4% of female patients,[6] and although many do not verbally disclose to their health providers their sexual orientation, most lesbians prefer that their health providers do know their orientation. Gay men face numerous health threats that need to be seen in their historical, cultural, and behavioral context. Historical stigmatism, discrimination, and rejection set the stage for psychological distress and substance misuse. The medical world has not always welcomed gay men, and in many parts of the world, good and safe care is difficult or impossible to come by. The increasing number of transgender, transsexual, and gender nonconforming people seen in health-care settings requires that health care providers understand how to manage them.

CARE FOR LESBIAN AND BISEXUAL WOMEN

Most research studies in lesbian health are based on self-identification rather than sexual behavior. Of the patient cohort that self-identifies as lesbian, about 30% are sexually active with men as well as with women; hence,

Box 32-1. Recommended Policies and Practices for Health Professionals

- Any patient could be LGBT or have LGBT family members:
  - Use inclusive language with all patients (e.g., ask a female patient about a possible "partner" rather than "boyfriend" or "husband," and ask a young person about his "family," rather than "mom and dad").
- Respond warmly on learning that patients, colleagues, or employees are LGBT, so that they do not fear bias or discomfort.
- Use LGBT patients' own language for themselves, rather than substituting other terms.
- Be sure not to make assumptions about individual LGBT patients based on stereotypes about LGBT people.
- Ask sensitively for more information if an LGBT patient uses phrases or mentions practices that are unfamiliar.
- Adopt history and intake records that allow LGBT patients.
  - To indicate they are partnered (rather than requiring "single" if they are not married)
  - Refer to "parent/guardian" (rather than "mother" and "father")
  - To indicate transgender status and/or preferred name and pronoun.
- Create a welcoming online and/or in-person environment by providing links or brochures about LGBT health, including LGBT images and symbols on webpages and walls, and posting LGBT-inclusive nondiscrimination policies where both patients and employees can readily see them.
- Have helpful referrals at hand for LGBT patients, including national and local groups providing targeted support for youth, families, elders, veterans, smokers, people of color, HIV+ people, actual and would-be parents, transgender individuals, and others.
- Signal support for LGBT patients by joining a directory of LGBT-friendly health-care providers, advertising via LGBT Web sites and publications, and/or displaying an "ally" pin, card, or sign.
- Arrange LGBT education (including lectures, brown bags, films, Web sites, and publications) for employees and colleagues.
- Seek out information about general and health-related LGBT topics by surfing Web sites, reading books and publications, and talking with LGBT friends.

it is important to consider counseling for prevention of unintended pregnancy. However, this counseling needs to be done in a sensitive manner, as intensive birth control counseling without regard to identified sexual orientation is often described as a reason that lesbians do not go back for follow-up visits to a provider. It is important to know that about 90% of all lesbians have had sex with men at some time in their lives. Whether or not a lesbian woman has sex with men, she may be interested in having a child, so preconception counseling should be offered to all lesbians (see the following subsections).

Sexually Transmitted Infections

Lesbians can have sexually transmitted infections (STIs), acquired through either their female or male partners. Chlamydia in young women is a public health epidemic, and can cause infertility in later years due to asymptomatic tubal scarring. Many public health departments recommend annual chlamydia and gonorrhea screening in all women younger than 26 years who are sexually active. There is one study that reported young adult lesbians had a higher prevalence of chlamydia infection than the heterosexual female cohort, mostly attributed to the observation that the lesbians had more sexual partners (some of whom were male) than the comparison heterosexual group.[7] HIV testing is now recommended for all women at least once in their lifetime. When lesbian patients are seen for the first time, if they have ever had sex with men, they should have age-appropriate gonorrhea and chlamydia screening, and all should have at least a one-time test for HIV. Further testing can then be individualized based on sexual behavior risk.

There have been rare but validated cases of HIV infection transmitted between women. Safer sex techniques have not been studied in lesbians; however, use of the female condom during high-risk times of menstruation, not sharing sex toys, and avoiding anal sex/tearing may be prudent at any time, and are strongly recommended in lesbian couples who are discordant for the HIV virus. Bacterial vaginosis can be transmitted between lesbian sexual partners. Infections that do not resolve or recur with treatment require evaluation of the partner. Genital herpes can also be transmitted between female sexual partners, and usual heterosexual precautions can be used with lesbians who have genital herpes.

Other Health Concerns

Lesbians tend to delay screening tests than heterosexual women, and women who self-identify as bisexual lag behind lesbian in screening rates.[8] Lesbians do exercise more than heterosexual women, but neither group exercises enough to meet national goals.[9] Lesbians have increased body mass index (BMI) about 1.5–2.0 times the frequency of increased BMI in heterosexual women, placing overweight/obese lesbians at increased risk for cancer, diabetes, and cardiovascular disease.[10]

Cancer

With the exception of breast cancer, cancer in lesbians has not been well studied. Breast cancer occurs at a slightly

higher rate in lesbians than in other women. Lesbians probably get mammograms at the same rate as heterosexual women but have fewer clinical breast exams. Risk factors for lesbians for breast cancer are the same as in heterosexual women. The increased risk may be related to an increased prevalence of alcohol use, higher BMI, higher incidence of smoking, and lower rates of childbearing and breastfeeding than among heterosexual women.

Since most lesbians have had sex with men at some point of time in their life, and because human papillomavirus (HPV) can be transmitted between women, Pap smears for cervical cancer screening are recommended according to the same professional society guidelines as for heterosexual women.

Reproductive Options

Increasing numbers of lesbians are childbearing, though often at an older age than heterosexual women. This means lesbians are at increased risk for infertility as well as at a possible increased risk of hypertension and diabetes in pregnancy, and their babies may have higher rates of birth defects. All women who plan pregnancies or who may get pregnant should have preconception counseling to include review of vaccinations and serologic testing for immunity for common infections that can cause fetal defects, review of medications and family genetic history, and advice on daily vitamins with folic acid (at least 0.4 mg/day), especially in the 3 months prior to conception. The majority of lesbians who are planning to become pregnant choose insemination from an anonymous donor for conception; however, some lesbians use known donors (e.g., male donor from the partner's family) or co-parent with men (e.g., a gay or heterosexual male friend[s]). Some lesbians in couples use "co-maternity" in which one lesbian donates an egg, it is mixed in the in vitro fertilization lab with sperm, and the embryo is placed into the uterus of her partner, such that both share biologically in the pregnancy.

There are many ways for LGBT parents to structure their families. State laws need to be considered when choosing a method of conception, especially regarding parental rights of the sperm donor if the conception or insemination occurs outside a physician's office. A potential lesbian parent should be encouraged to consult with a local family attorney prior to conception if possible. The National Center for Lesbian Rights has important information for potential LGBT parents (www.nclrights.org). Most fertility practices are now accessible for lesbian clients. Adoption is governed by state laws and may or may not be an option for a single lesbian parent-to-be or those in a couple.

Many studies have now been done on the outcomes of children raised by lesbian parents. They verify that the emotional, psychological, and physical well-being of children raised by lesbians equals or exceeds that of children raised by heterosexual parents.[11]

Mental Health

Lesbians have higher rates of depression compared with heterosexual women, particularly if they belong to a racial minority. Other types of mental illness are probably present at the same prevalence as for heterosexual women. Domestic violence rates are probably the same for lesbian couples as for heterosexual women.[12] Many women including lesbians have been sexually assaulted in the past. Studies have documented slightly increased rates of childhood sexual abuse in lesbians.[13]

The increased rate of depression has been attributed to the daily homophobia that many lesbians experience.[14] Lesbians are comparatively more likely than heterosexual women to use psychotherapy than medications for treatment of their depression. A recent study revealed that there was an increased rate of attempted suicide in LGB persons who sought out religious or spiritual counseling, compared with those who used mental health or medical treatment services.[15] Therefore, it is critical that lesbians do not get referred to homophobic therapists or mental health clinics.

Substance Use

Lesbians have increased rates of smoking, alcohol consumption, and substance use. A complete history therefore needs to be taken, and if injection drugs have ever been used then appropriate hepatitis and HIV testing should be done.[16] Their smoking rate is two to three times that of heterosexual women,[17] so they should be screened for cigarette smoking at each medical visit. Referrals for drug and alcohol treatment, just as for all mental health referrals, need to be sensitively made. Many lesbians are in recovery, but not all Alcoholics Anonymous (AA) or other recovery groups or programs are welcoming to lesbians. In large cities, it is often possible to find lesbian AA and other recovery and support groups.

CARE FOR GAY AND BISEXUAL MEN

Sexual expression became incredibly risky with the spread of HIV, and much of gay male health is currently centered on prevention and management of HIV infection. It is important to be aware that not all men who have sex with men (MSM) identify as gay, and that there may be unique issues for MSM who identify as bisexual or heterosexual. Bisexual men and women may experience less social support than their homosexual or heterosexual peers, not feeling fully accepted by either community. This section addresses some of the challenges to health experienced by gay men, MSM, and bisexual men and provides an overview of priorities in their care.

Mental Health

The majority of gay men do not experience problems with mental health. However, anxiety and depression likely do occur at a higher rate than in the general population, up to 1.5 times more frequently in some studies (see the Institute of Medicine's 2011 report on LGBT health for an overview of the study of mental health in LGBT communities).[18] The risk of suicide in LGBT teens has been well publicized in the United States, and an elevated risk likely persists into adulthood, with an overall lifetime risk of suicide more than twice as high as for heterosexuals.

It is important to note, however, that not all studies have found higher rates of psychological distress across the board in gay as compared to straight men. Measures of well-being such as happiness and job satisfaction reveal similar findings for men across the sexuality spectrum. The relationship between sexual orientation and mental health is nuanced—for example, Bostwick et al[19] found gay men had a higher prevalence than heterosexual men of any lifetime mood disorder (42.3% vs. 19.8%) and of any lifetime anxiety disorder (41.2% vs. 18.6%). These rates, however, were mediated by the degree of same-sex attraction: men (and women) reporting exclusive same-sex attraction reported lower rates of psychological stress than did those with less exclusive attraction or behavior. Bisexuality was associated with the highest rates of mood disorders. Regardless of where people fall on the spectrum of sexuality, the mental health of LGBT populations will likely improve in parallel with advances in societal support and acceptance.

Substance Use

Substance misuse and abuse is also more prevalent in gay men and MSM. Smoking may be up to twice as common among gay men as heterosexual men, and black gay or bisexual men have almost double the smoking prevalence of heterosexual black men (62% vs. 34%).[20] Data are mixed on the rates of drug and alcohol use by gay men—studies have found higher levels of both use and dependence. Heavy marketing of cigarettes and alcohol to the gay community encourages overuse. Use of the acronyms "PNP" (party and play) and "Chem Friendly" in personal adds by men seeking a male partner reflects a culture where drugs and sex are commonly linked.

Of particular concern is the use of drugs or alcohol to negotiate and facilitate unprotected sex. Among black MSM who do not identify as gay, drug and alcohol use or exchange play a significant role in promoting unprotected sex. A study of men in methamphetamine and cocaine addiction programs found that within the first few months of treatment, the number of reported sex partners fell from a mean of approximately seven to one per month. In the same study, unprotected anal intercourse decreased from 70% to 24% of encounters.[21] MSM accustomed to sex while using stimulants often describe sex without drug use as lacking pleasure and excitement.[22] This experience has direct implications for treatment and relapse prevention programs.

HIV Risk and Prevention

Infection rates and risk among MSM

HIV education and prevention efforts depend first on understanding risk. Risk remains disproportionately high among MSM, and in particular among younger MSM and racial and ethnic minorities. Although MSM represent less than 10% of the US male population, in 2010 they accounted for 78% of new HIV infections among men and 63% of all new infections. While the overall incidence of HIV infection in heterosexuals and injection drug users in the United States has stabilized or declined, there has been a 12% increase in the rate of new infections among MSM. Young black MSM account for 55% of new infections in young men, and Latino/Hispanic men are infected at 2.9 times the rate of white men.[22]

In 2011, an estimated 18% of all MSM were infected. Thirty-four percent of these men were unaware of their infection, and those who did not know their HIV status were more likely to have unprotected sex.[23] The National HIV Behavioral Surveillance System (NHBS) found the number of MSM who had unprotected anal sex at least once in the past 12 months increased from 48% in 2005 to 57% in 2011. Estimated per-act risk of sexual acquisition of HIV by MSM not using condoms are listed in Table 32-1.[24]

Preventing HIV transmission

Education, condom promotion, and broader treatment of HIV-infected individuals all have an impact on sexual practices and transmission rates. Consistent condom use reduces the risk of acquiring or transmitting HIV by about 80%.[25] Adherence to antiretroviral medication reduces HIV transmission by up to 96%.[26] And when serodiscordant couples (one HIV positive, one negative) use condoms reliably and the HIV(+) partner takes effective HIV medication, the transmission risk can be reduced by 99.2%.[27] Nonetheless, overall HIV infection rates among MSM have increased in recent years. This has encouraged research into the use of medication by HIV-negative men to reduce their risk of becoming infected, particularly as postexposure treatment of needle stick and other occupational exposures as well as perinatal prevention strategies using HIV medications have been shown to be highly effective.

Table 32-1. Risk of HIV Transmission by Route of Exposure

Route of Exposure	Risk of HIV Transmission
Receptive anal intercourse	0.3–3.2%
Insertive anal intercourse	0.06–0.62%
Receptive oral intercourse	1 (0.01%)–limited data
Insertive oral intercourse	0.5 (0.005%)–limited data

Nonoccupational postexposure prophylaxis is the use of highly active antiretroviral therapy to reduce the risk of becoming HIV infected following sexual exposure, injection drug use, or other exposure occurring outside of the occupational setting. While there is no direct data on use for this purpose, a potential benefit is inferred from data in animals, occupational and perinatal settings, and observational studies. The US Centers for Disease Control recommends postexposure prophylaxis be started within 72 hours of unprotected sexual intercourse with someone known to have HIV. When the HIV status of the sexual contact is not known, the decision whether or not to treat must be made on a case-by-case basis.[28] Treatment should be continued for 28 days, unless the source patient tests negative. The recommended medication regimen has changed over time (see Clinician Consultation Center [http://nccc.ucsf.edu/]) for detailed up-to-date guidelines and consultation services.

Preexposure prophylaxis (PrEP) is the daily use of antiretroviral medications by a sexually active uninfected individual to reduce the risk of acquiring HIV. In contrast to postexposure prophylaxis, there is high-quality study data demonstrating the effectiveness of PrEP. A major study on which guidelines are based found that sexually active MSM who took PrEP were 44% less likely overall to get HIV than those who took placebo. For those who took the medication consistently (as evidenced by detectable levels in their blood), the risk reduction was up to 92%.[29] On the basis of these data, the US CDC released guidelines in 2014 recommending PrEP use for MSM who are at a substantial risk for acquiring HIV (Box 32-2).[30] These guidelines may be appropriately applied to high-risk transgender women as well.

Currently, a single pill containing the medication combination tenofovir and emtricitabine (Truvada™) taken once daily is recommended for PrEP in the United States. No serious adverse reactions have been demonstrated, and side effects (nausea, loss of appetite, headache) tend to be mild and to resolve within the first month of use. To avoid unintentional treatment of active HIV or hepatitis B, a patient should have a negative HIV test within the week before starting therapy, and up-to-date testing and immunization for hepatitis B. For those treated with tenofovir, renal function testing is recommended at baseline and every 6 months. HIV testing should continue every 3 months.

It should be noted that fears that the use of PrEP would further promote unsafe sexual practices have so far not come to pass. Although there are limited data to date, STI rates have not increased in men taking PrEP, and many men report the daily process of taking prophylaxis serves as a reminder of HIV risk and reinforces the importance of self-care and healthy living.

Box 32-2. Recommended Indications for PrEP Use by MSM

- Adult man
- Does not have acute or established HIV infection
- Has had male sex partners in the past 6 months
- Is not in a monogamous relationship with a recently tested, HIV-negative partner AND one or more of the following:
- Any anal sex without a condom (receptive or insertive) within the past 6 months
- Any STI within the past 6 months
- Is in a sexual relationship with an HIV(+) partner

From US Public Health Service. Preexposure Prophylaxis for the Prevention of HIV Infection in the United States—2014: A Clinical Practice Guideline. http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf.

Other Sexually Transmitted Infections and Hepatitis

Because of more unprotected sex, STI rates have increased alongside new HIV infections among MSM in the United States and other industrialized countries. Gonorrhea (GC), chlamydia, and syphilis screening should be performed at least annually in sexually active MSM with any risk for infection, and in high-risk MSM (e.g., multiple partners, active substance abuse), screening as frequently as every 3 months may be indicated. Because asymptomatic infections are common, pharyngeal, rectal, and urethral testing for GC and chlamydia are all recommended. Hepatitis A and B testing and immunizations are recommended for all MSM. Hepatitis C virus (HCV) can be spread sexually, more commonly in HIV(+) men, so testing for HCV should also be considered.

Anal HPV occurs at high rates in MSM who have receptive anal intercourse; consequently, MSM, especially those who are HIV infected, are at an elevated risk for anal cancer. Though the United States does not have national guidelines recommending routine screening for anal dysplasia and cancer, many experts advocate doing so. HPV vaccination has been approved for the prevention of anal cancer and should be offered to all young MSM.[31]

CARE FOR TRANSGENDER PATIENTS

Transgender, transsexual, and gender nonconforming people have been noted throughout history and human societies. They are estimated to make up 0.3–1.4% of the general population[32-34] and numbers of transgender people seen in health-care settings are rising.[35] The health care of transgender individuals requires practice adaptation and knowledge in three areas: (1) understanding the diversity of gender identity and expression; (2) providing comprehensive care for gender dysphoria; and

(3) assisting patients with care for the results of widespread severe discrimination.

Diversity of Gender Identity and Expression

Transgender refers to people whose gender identity and expression are different from the cultural and social expectations of the sex they were assigned at birth. This term can encompass a full range of different identities and possibilities (Note: Not everyone described by our use of the term uses this term to describe themselves). In this chapter, the term transgender woman is used to include individuals who were assigned to male sex at birth and who identify as female and/or take action to feminize themselves medically or surgically. The term male-to-female is also used. Transgender man is used to include transgender, transsexual, and gender nonconforming individuals who were assigned to female sex at birth and who identify as male and/or take actions to masculinize themselves medically or surgically. The term female-to-male is also used. Current evidence-based concepts of sex and gender reveal a spectrum of diversity. This spectrum has been conceptualized as a "gender galaxy" (Figure 32-1).

Gender Dysphoria

Gender dysphoria occurs when gender identity causes distress. Various psychosocial, medical, and surgical interventions have been found to relieve gender dysphoria. Medication that causes masculinization or feminization is one intervention used by some people. Some people have some form of sex reassignment/gender affirmation surgery. Others do not. For transgender people to live in good health requires that they experience and express their gender in as fulfilling a way as possible. (Of course, this is true for everyone but is usually not an issue for those whose gender identity and gender expression conforms to cultural norms.)

The CDC and others have recommended a two-question method for recording sex and gender in health records to facilitate clinical care, epidemiology, and research (Box 32-3).[36]

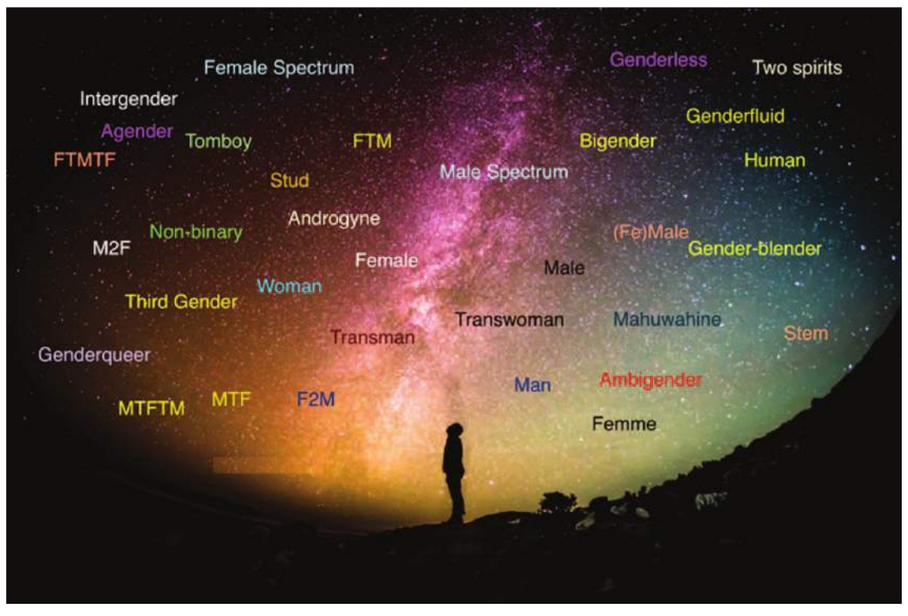


Figure 32-1. Gender galaxy. Concept Julie Graham and Dylan Blade; background photograph Greg Rakozy. https://stocksnap.io/photo/Y8CKB0O8C2.)

Box 32-3. Two-Question Method for Recording Sex and Gender in Health Records

1. What is your gender? (Check one that best describes your current gender identity.)
   i. Male
   ii. Female
   iii. Trans male
   iv. Trans female
   v. Not listed, please specify.
   [Survey forms would include options 1–5. Coding should also allow for options 6 and 7]
   vi. Declined/Not stated
   vii. Question not asked
2. What was your sex at birth? (Check one)
   iii. Male
   iv. Female
   [Survey forms would include options 1–2. Coding should also allow options 3 and 4.]
   v. Declined/Not stated
   vi. Question not asked

Discrimination

Transgender people are subjected to severe discrimination in most societies. Discrimination has been well documented in health care, education, employment, and interpersonal settings.[37] Bullying and physical and sexual abuse starting in childhood are frequent. Hate crimes, including murder, are unfortunately common.[38] Discrimination, harassment, and violence result in transgender people having high rates of stress and trauma-related behavioral health problems. Common issues include depression, anxiety, Post-traumatic Stress Disorder (PTSD), and adjustment disorders and substance use. High-risk behaviors and suicidality, especially in transgender youth, are common. High levels of criminal justice system involvement and high risks of HIV infection and other sexually transmitted diseases (STDs) have been shown in transgender women and are likely present in transgender men as well.

Transgender patients often do not receive recommended preventative care and care for medical conditions. This may be due to discrimination, isolation, and shame. Medical care and preventative services need to be given based on a patient's age, anatomy, and risk factors. In many cases, the patient's gender identity is irrelevant to the presenting medical need and does not need to be addressed beyond the obvious courtesy of using the patient's preferred name and pronouns. Excess curiosity about a person's gender and sex, asking patients to educate providers

about what it is like to be transgender, or using patients as teaching examples are unfortunately common experiences that drive patients away from seeking health care.

In providing primary care, in addition to a standard health history, additional relevant medical history will include history of gender experience, prior hormone use, prior surgical history, sexual history, and the patient's goals related to health and gender transition. Psychosocial needs assessment will include mental health history, information about family and other social support or estrangement, alcohol and drug use history, criminal justice involvement, history of past and current suicidality, and support from and knowledge about the transgender community. In performing a physical exam, it is necessary to be mindful of previous trauma and abuse. Avoid breast, rectal, and genital exam on initial visits. Initial laboratory screening for transgender patients is based on age, anatomy, and risk factors.

Medical Risks of Transgender People

Health promotion and disease prevention is based on recognized risks and common problems. In general, care of acute and chronic diseases does not differ in transgender people. Health-care providers must understand that gender dysphoria may be very severe and measures to relieve the associated suffering may need to be balanced against or addressed before other health priorities. High rates of risk behavior including unprotected anal receptive intercourse have been documented in transgender men.

Very high rates of HIV, STIs, and sexual violence have been documented in transgender women and especially in African-American transgender women. Rates of depression, mental illness, and substance use are also high in transgendered people. It is therefore recommended to assess for depression, substance use, high-risk sexual behavior, HIV, and STI risks and provide counseling and services to reduce risks. Specific questions about sexual practices and preferences in terms of sexual functioning and fertility also are required as patients may be unaware of the possibility of themselves or a partner becoming pregnant unintentionally or through assisted techniques. Counseling patients on strategies for disclosing their anatomy to potential partners as a way of avoiding violence is also recommended.

No authoritative HIV or STI screening guidelines for transgender men or women are available. Owing to a high incidence of new infections, the San Francisco Department of Public Health (SFDPH) and others recommend performing STD screening every 3–6 months for sexually active transgender patients.[40] Some programs working with mixed of high-risk and lower-risk transgender populations suggest asking every patient if they need STD screening at every visit. This may be a reasonable alternative to universal screening and good entry point to safer sex counseling (Table 32-2).

Table 32-2. STD Screening Recommendations for Transgendered Patients Every 3–6 Months for High-Risk Patients[39]

Screening Test	Transgender Men	Transgender Women
HIV, syphillis screening	□	□
Pharyngeal, urine and rectal GC, chlamydia		□
Pharyngeal, rectal and vaginal GC, chlamydia	□	

Body Image

Transgender people may seek to change their body image by hormones, plastic surgery, and other measures (see later). While many of these methods are safe in experienced hands, other methods, particularly those done outside of usual medical practices, may be problematic. For example, transgender women, especially Latina transgender women, may attempt to obtain desired body changes by having silicone or other substances injected into their bodies by illicit operators. Educating transgender women and the community about the serious health risks of these practices, including permanent body deformity and death, may help decrease this practice.[41] Transgender men will frequently use tight breast binding to approximate the flat appearance of a male chest. Long-term breast binding may reduce elasticity of chest tissue and interfere with good outcomes in chest reconstruction surgery. Overly tight binding may interfere with lung function, cause rib pain, or even rib fracture. Transgender women may "tuck" their penis, scrotum, and testes posteriorly and into the inguinal canal. Risks of tucking have not been well described in medical literature. Skin irritation and increased susceptibility to candidal intertrigo have been described anecdotally. Patients who push testicles into the inguinal canal are at risk of inguinal hernia and testicular pain possibly neuropathic in origin.

Cancer

Cancer screening such as Pap smears and mammograms and other transgender population-specific health maintenance have not been studied and remain controversial. Best practices have been developed and are available (see "Resources"). In general, recommendations parallel those in non-transgender populations. Screening for breast, cervical, uterine, and prostate cancers may exacerbate issues of gender dysphoria and require particular sensitivity in this population.

There are no evidence-based established guidelines for breast cancer screening; consequently, cancer screening according to established guidelines for all patients with breast tissue is reasonable. Breast cancer incidence in transgender women who have had hormone therapy appears to be very rare, although possibly higher than in

men. Breast cancer incidence in transgender men, whether exposed to testosterone hormone therapy or not, does not appear to differ from women. Transgender men who have had subcutaneous mastectomy with male chest construction surgery still have some breast tissue and therefore continue to have risk of breast cancer. It is unclear what, if any, breast cancer screening beyond awareness should be offered to this group. SFDPH guidelines for transgender women who have taken estrogen hormone therapy recommend following standard guidelines for women, and beginning screening with mammograms for patients older than 40 or 50 years in those who have been exposed to estrogen (endogenous or exogenous) for 20 years or more, or earlier if abnormal findings or family history of breast cancer. Other experts have used 5 years as minimum period of estrogen exposure for screening.

Cervical cancer screening is recommended according to standard guidelines for all patients who have a cervix (i.e., transgender men who have not undergone hysterectomy with removal of cervix). Transgender women (including those who have had vaginoplasty) do not require a cervical Pap smear. When cytology is sent in transgender men, the provider must note if a patient is taking testosterone to avoid errors in interpretation. For those patients who are unable or unwilling to undergo vaginal exam, using self-swab for HPV is an alternative.

Endometrial hyperplasia and uterine cancer are risks for transgender men with an intact uterus who are receiving testosterone. No screening measures are ideal. Endometrial biopsy or assessment of the endometrial lining thickness by ultrasound is recommended for transgender men with a uterus if they have bleeding after a long period of amenorrhea and they have not had an interruption of or change to their testosterone dose.

Transgender women who have been exposed to antiandrogen hormone therapy or surgery are expected to have lower risk for prostate cancer than men. Nevertheless, due to the high prevalence of prostate cancer, development of prostate cancer is still possible even in transgender women who have had any type of vaginoplasty, as these procedures leave the prostate intact. The evidence for prostate cancer screening in the general population is controversial. Hence, how to apply screening to transgender patients is even less clear. Patients with low testosterone levels will have suppressed prostatic-specific antigens (PSAs) and following PSA levels is not useful in this situation.

> Dr. Nguyen acknowledges the severe discrimination faced by transgender people and her appreciation of the challenges faced even in coming to the doctor's visit today. She asks Mr. S. what his preferred name and gender pronouns are. She obtains his medical history including history of gender and sexual identity and sexual practices because these may be relevant to his health and need for services such as cervical cancer screening. He has many questions including questions about hormone treatment for gender dysphoria. Dr. Nguyen explains that she is not an expert in transgender health but she knows resources for information and will be able to care for him.

Care for Gender Dysphoria

Outcomes for patients with untreated gender dysphoria are poor. The decision of transsexual, transgender, and gender nonconforming people to take hormone therapy or undergo various transgender surgeries to treat gender dysphoria is based on personal preferences and medical need. Many patients are highly motivated to take hormones or have surgery. Other health and life considerations are considered of secondary importance. If medically supervised treatment is not accessible, many patients will obtain hormones illicitly. If surgical treatment is not available, some patients will resort to seeking out untrained surgeons, illicit injections of silicone or other substances, or self-mutilation.

The World Professional Association for Transgender Health (WPATH, http://www.wpath.org/) publishes updated evidence-based standards of care that are considered the internationally accepted guidelines for treatment of gender dysphoria. The most recent version (WPATH SOC 7) was released in July 2012.[42] This version emphasizes addressing needs of underserved patients in the developed and developing world and is being released in numerous languages. WPATH SOC 7 underscores the importance of informed consent for all interventions and recommends when it is advisable for primary care physicians to prescribe hormone therapy for patients who have not had mental health assessments.

Hormone Therapy

Hormone therapy is not required to make complete legal gender transition in some states and countries. Other jurisdictions do mandate specific interventions or surgeries to allow changes to birth certificate information.[43] Research on hormone therapy for transition of gender has slowly advanced. Evidence-based international guidelines are available from the Endocrine Society[44] and UCSF Center of Excellence for Transgender Health.[45] Guidelines and protocols are available with adaptations for specific underserved populations (see "Resources").

Well-informed patients with realistic expectations have the best results from hormone therapy. Key points in education of patients starting any hormone therapy are included in Table 32-3. Details of expected and adverse effects, monitoring, and follow-up for each agent are beyond the scope of this chapter but are accessible via Web sites such as those cited in the "Resources" section, or the following link: http://www.sfdph.org/dph/files/THS/HormoneTherapyRev.pdf.

Table 32-3. Education of Transgender Patients Starting Hormone Therapy

1. Well-informed patients with realistic expectations have the best results from hormone therapy.
2. Some effects of hormone therapy are permanent and irreversible.
3. Medication used for hormone therapy have expected desirable effects (e.g., demasculinizing, feminizing, defeminizing, masculinizing) and possible adverse effects.
4. People have individual hopes and desires for the effects of hormone therapy.
5. Each person responds differently to each different medication.
6. Factors influencing the positive or negative effects of a medication include age when starting, dose, cigarette smoking, other medical problems, other medications, alcohol and drug use, the genetic background of the patient, and the risk that others close to the patient could be exposed (e.g., topical testosterone.)
7. Patients and their medical providers must discuss expectations and limitations of each therapy.
8. Side-effects range from the common to rare, mild to serious, and documented to theoretical.
9. For patients to give informed consent, they must have education that clearly reviews these distinctions.
10. Effects on mood, behavior, and sexuality are variable between patients and are usually most notable when starting or stopping abruptly.
11. Psychological well-being must be addressed before starting hormone therapy or changing doses.
12. Support from family, friends, a therapist, others in the transgender community, and avoiding other severe concomitant stresses may be helpful.

Historically, the greatest barriers to prescribing hormones have been discrimination and health-care providers' lack of knowledge. Prescribing and monitoring hormone therapy for treatment of gender dysphoria is now commonly done in primary care practices; especially those that have or can collaborate with multidisciplinary behavioral health clinicians.[46] Previous fears regarding very high risks of adverse effects, especially thromboembolism caused by estrogen therapy, have been reduced by evidence that morbidity and mortality in transgender people is not increased by currently recommended hormone therapy.[47] Offering hormone therapy in primary care settings can prevent the serious sequelae of untreated gender dysphoria and delivers health care to individuals who may previously have avoided health-care providers. The existence of evidence-based guidelines from WPATH and respected universities and public health departments should reduce the barriers to this service. Clinicians involved in this care often report this is one of the most satisfying aspects of their practice.

Hormone therapy does not generally affect the treatment of other health conditions including HIV disease, diabetes, and other chronic medical conditions. Very few, if any, clinically significant drug–drug interactions occur between commonly used hormones and current HIV antivirals or treatments for other chronic diseases. Nor are there important interactions between hormone therapy and street drugs. Were hormone therapy to possibly exacerbate an illness, for example, risk of weight gain from testosterone or estradiol in a patient with diabetes, it is necessary to balance this risk with the benefits of treating gender dysphoria.

Loss of fertility is a possible adverse effect of hormone therapy and an inevitable effect of most genital transgender surgeries. Maintenance of the possibility of biological parenting is possible for many transgender people with current fertility technology. Counseling and education related to fertility is recommended for all patients considering hormones or surgery. Unfortunately, even the least expensive fertility interventions such as sperm banking for transgender women are beyond the means of many transgender patients and are usually not covered by public or private health insurance.

Some patients choose to undergo transgender surgery (also known as sexual reassignment surgery, gender reassignment surgery, genital reconstruction surgery, sex affirmation surgery, gender confirmation surgery, or sex realignment surgery). Use of language such as "pre-op" or "post-op" when referring to transgender individuals is inaccurate and potentially harmful, as there are many types of surgeries and many patients whose gender goals do not include any surgery at all. There is a range of transgender surgeries. Common masculinizing surgeries include subcutaneous mastectomy with male chest construction, metoidioplasty, phalloplasty, and hysterectomy with or without removal of tubes/ovaries. Common feminizing surgeries include feminizing mammoplasty (breast augmentation), orchiectomy, vulvoplasty, vaginoplasty, and facial feminization surgery. Guidelines for the role of medical providers, mental health professionals, and surgeons have been established by WPATH.[43]

Appropriate education and preparation for surgery is essential for best outcomes. Guidelines and adaptations for education and preparation for transgender surgery in underserved populations are available (see "Resources"). Important outcomes to discuss with patients include information about surgical morbidity and mortality, recovery time, postoperative care, possibility that additional surgeries will be needed, likely physical appearance (with and without clothing) and ability to avoid harassment and abuse due to physical appearance, visible scars, and sexual and urinary functioning.

CONCLUSION

Medical knowledge and acceptance of transgender people have improved in many areas in the past few years. Access to health care is improving. Elimination of specific exclusions for transgender care promises to further improve this situation. Several states and many corporations and universities now require all insurance to cover

Box 32-4. Common Pitfalls in the Care of LGBT Patients

1. Lack of awareness that LGBT patients are in every health-care setting and often do not conform to stereotypes
2. Risk assessment based on LGBT stereotypes, not behavior
3. Exclusion of same-sex partners or nontraditional family members from discussions and decision making
4. Assumption that that LGBT patients do not have or are not planning for children
5. Violation of confidentiality
6. Not addressing the complex psychological issues that sometimes exist between sexual activity and substance use, limiting the effectiveness of interventions to reduce drug and alcohol use or to promote safe sex
7. Lack of familiarity with treatment of gender dysphoria
8. Assumption of stereotypical sexual orientation and gender identity by health-care providers and health-care systems

transgender-related care.[48] In the United States, Medicare has eliminated exclusionary barriers to transgender surgery. Robust advocacy is underway to further decrease discrimination particularly in health care. Reliable and information-rich resources are now available or under development. Health-care providers must be equipped to offer patient-centered care to LGBT patients, who face particular challenges in health care (Box 32-4).

- LGBT patients fear bias and discomfort on the part of health-care providers, but health professionals can do much to lessen this concern.
- Gender identity is not binary male or female.
- Transgender people are severely impacted by discrimination.
- Gender dysphoria requires treatment.
- Education, counseling, hormone therapy prescription, and participation in a team assisting patients to make decisions about transgender surgery are appropriate and fulfilling activities for primary-care health providers.
- Younger MSM and MSM of color are at disproportionate risk for acquiring HIV. Counseling, education, and prevention measures should be focused on this population.
- Medication taken prophylactically to prevent HIV infection is highly effective and should be considered in all sexually active MSM and transgender women.

Sample Questions to Adapt to LGBT-Sensitive History Taking or Intake Forms

Sexual activity
- Are you sexually active?
- Are you sexually active with men, women, or both?
- Have you ever had sex with a man (woman)?
- How many sexual partners have you had in the past year?
- How many sexual partners have you had in your lifetime?

Safe sex, sexually transmitted infections, and human immunodeficiency risks
- Do you use any safe-sex methods?
- Do you have any questions about safe sex? With men, women, both?
- Have you ever had an STI? Which one(s)? When?
- Have you ever injected drugs, or had sex with someone you know has injected drugs?
- Have you ever had an HIV test? When? What was the result?

Sexual identity and relationships
- How do you identify your sexuality (circle all that apply): lesbian, gay, bisexual, transgender, heterosexual, celibate, not sure/don't know?
- Are you currently in a relationship?
- Are you single, significantly involved, domestic partner, married, separated, divorced?
- If you are lesbian, gay, bisexual, or transgender are you "out" to friends (all? some?), family (all? some?), work, all of the above, none of the above?

Living situation, family, and children
- Do you live alone or with others? With whom?
- Do you have children?
- Are you interested in having children?

For gender-identity see Box 32-3

DISCUSSION QUESTIONS

1. What types of challenges might a lesbian or gay man face when seeking health care? What is your role in addressing these challenges?
2. What can you do in your practice to decrease discrimination against transgender people?
3. Why is it often hard to discuss sexual orientation and sexual behavior in a medical visit? What about gender identity? Discuss ways you might frame and discuss these issues with patients.
4. How might systemic barriers to accessing and receiving good care be reduced LGBT patients? In your own practice, what specific measures can you take to promote comfort and open communication?

RESOURCES

Publications and Other Resources from the Lesbian, Gay, Bisexual and Transgender Concerns Office. American Psychological Association Web site. http://www.apa.org/pi/lgbt/resources/public-info.aspx.

Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: Institute of Medicine; 2011. www.iom.edu/LGBTHealth.

US Public Health Service: Preexposure prophylaxis for the prevention of HIV infection in the United States—2014. A Clinical Practice Guideline: http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf.

Clinician Consultation Center: http://nccc.ucsf.edu/. UCSF-based program providing online and phone-based consultation in service areas including testing and prevention, treatment, and post-exposure prophylaxis. Extensive online resource links.

Gay and Lesbian Medical Association. GLMA's mission is to ensure equality in health care for lesbian, gay, bisexual, and transgender (LGBT) individuals and health-care providers. http://www.glma.org/.

Human Rights Campaign. Largest U.S. LGBT rights organization provides general LGBT information and administers. National LGBT Healthcare Equality Index, which offers numerous recommendations for LGBT patient-centered care. http://hrc.org/hei.

World Professional Association for Transgender Health. http://www.wpath.org/.

SFDPH Transgender Health Services. https://www.sfdph.org/dph/comupg/oprograms/THS/ClinicalResources.asp.

UCSF Center of Excellence for Transgender Health http://transhealth.ucsf.edu/.

Transline Project: http://project-health.org/transline/.

Vancouver Coastal Health: transhealth.vch.ca.

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Chapter 33

The Medical Treatment of Patients with Psychiatric Illness

Christina Mangurian, MD, J. Ryan Shackelford, MD, and James W. Dilley, MD

Objectives

- Review the increased mortality for people with severe mental illness (SMI).
- Discuss common medical comorbidities among people with SMI, including cardiovascular disease, metabolic syndrome, nicotine dependence, substance abuse, HIV, and hepatitis C.
- Discuss common psychiatric comorbidities among people with medical conditions, including depression, anxiety, and substance abuse.
- Review effective health-care delivery models for integrating primary care and behavioral health.

INTRODUCTION

Almost 1 billion people worldwide and over 25% of US adults suffer from a mental illness.[1] Those with mental illness have higher rates of death, disability, medical illness, incarceration, homelessness, unemployment, poverty, and violation of their human rights. Exposure to humanitarian crises, natural disasters, violence, poverty, and chronic illness increase the likelihood of mental illness.

Lack of access to mental illness care is very common—treatment rates range from 13% to 33% in high-income countries, and from 5% to 13% in low- and middle-income countries.[2] When mental illness co-occurs with other medical conditions, it complicates treatment of both conditions. Unfortunately, even with access to care, medical disorders in people with severe mental illnesses (SMIs) often go undiagnosed and untreated, and conversely, mental disorders in people with medical conditions often go undiagnosed and untreated. Overall, medical costs are higher for people with mental illness.[3,4] For example, people with diabetes and comorbid depression have health-care costs that are 4.5 times higher than those without depression.[4]

Since the majority of people with mental illnesses are served in primary care, this chapter is dedicated to helping primary care providers improve the medical care received by this vulnerable population.[5] First, we review common medical comorbidities of people with SMIs and suggest guideline-concordant screening and treatment strategies. Second, we discuss the psychiatric comorbidities commonly afflicting people with medical conditions, and suggest screening tools to identify these illnesses. Third, since many people with HIV are treated in primary care, we have a special section dedicated to psychiatric comorbidities among people living with HIV. Finally, we discuss models for integration of mental and physical health that can assist administrators of health-care systems serving these patients. Although we concentrate on the US population, many of the issues we raise have relevance globally as well.

MEDICAL COMORBIDITIES AMONG PEOPLE WITH SEVERE MENTAL ILLNESSES

Ms. Jones is a 35-year-old African-American woman with schizophrenia and a history of multiple psychiatric hospitalizations. She has limited insight into her mental health condition, but does take risperidone 2 mg twice a day. She presents to the primary care clinic at the urging of her case manager.

Box 33-1. Common Risks and Pitfall for Patients with Mental Illness

- Higher rates of death and disability
- High risk of social vulnerabilities: homelessness, violence, incarceration, poverty, and unemployment
- Higher rates of medical illness and premorbid conditions that often go undiagnosed and treated
- Higher rates of mental illness in patients with chronic illness that often go undiagnosed and treated
- Treatment with second-generation antipsychotics increases the risk of obesity, diabetes, and metabolic syndrome in patients with SMI

In 2012, the prevalence of SMI (e.g., schizophrenia, schizoaffective disorder, bipolar disorder) was approximately 4% of the US population, or 9.6 million people nationwide.[6] Although the majority of these patients are cared for in specialty mental health-care settings, primary care physicians—particularly those serving safety-net populations—often provide care to these patients.[5,7]

Primary care providers may be unaware that people with SMI are among the most vulnerable groups in society (Box 33-1). For example, people with SMI die, on average, 25 years earlier than the general population, most often from cardiovascular disease (CVD).[8] Although the causes of this premature death are multifactorial, some of the responsibility rests on the shoulders of medical providers—since there are major gaps in screening and treatment of preventable disease.[9] In fact, 87% of the years lost are from treatable medical conditions.[8]

These medical conditions are associated with modifiable risk factors including smoking, obesity, substance abuse, psychotropic medication side effects, and inadequate access to medical care. Considering that primary care physicians do provide care to people with SMI, it is essential that primary care providers have expertise in the common medical illnesses in this population and provide appropriate screening that impact long-term outcomes (Box 33-2).

CARDIOVASCULAR DISEASE, THE METABOLIC SYNDROME, AND DIABETES

> Ms. Jones gets her vitals done by the medical assistant. She is found to be overweight with an elevated blood pressure.

People with SMI have higher rates of CVD and the metabolic syndrome than the general population.[10] About 40% of all deaths of people with SMI are from CVD, which is higher than the general population (30%).[8] In one large trial, the 10-year coronary heart disease risk was significantly higher among people with schizophrenia than among a general US population sample,[11] as was the prevalence of the metabolic syndrome.[12] Studies also indicate that the prevalence of diabetes among people with SMI is two to three times higher than the general population.[13] In fact, a meta-analysis showed that people with SMI have a 70% increased risk of diabetes compared with the general population.[14]

Box 33-2. Annual Medical Screening Guidelines for People with Severe Mental Illness, Regardless of Age

- Weight (body mass index [BMI])
- Blood pressure
- Fasting plasma glucose
- Lipid panel
- HIV test
- Hepatitis C test (if risk factors present)
- Nicotine-dependence screening
- Substance abuse screening

Some second-generation antipsychotic (SGA) medications contribute to CVD by increasing risk of obesity, diabetes, hypertension, and dyslipidemia. Because the evidence for medication-related metabolic risk was so compelling and because SGAs are so widely used,[15] the American Diabetes Association (ADA), the American Psychiatric Association (APA), and others recommended that annual metabolic screening be performed for anyone taking these medications, regardless of age or predisposing factors.[16] Specifically, ADA/APA guidelines recommend quarterly weight/BMI measurements; and annual monitoring of blood pressure, fasting glucose, fasting lipids (if high risk), and waist circumference (Table 33-1).[16] Unfortunately, 10 years after publication of these guidelines, up to 70% of those on antipsychotics remain unscreened or undermonitored for metabolic abnormalities.[17]

This lack of screening is particularly concerning for subpopulations that may be at greater risk of metabolic side effects of these medications, namely, children/adolescents, women, and minorities.[12,18] We recommend adherence to ADA/APA recommendations with annual metabolic screening of people with SMI taking antipsychotic medications, regardless of age (Table 33-2).

It is worth noting that even when diabetes or other metabolic risk factors are identified, people with comorbid diabetes and SMI are less likely to receive evidence-based diabetes care than people without SMI.[19] In one Veteran's Administration (VA) study, only 11% of people with comorbid diabetes and SMI received treatment.[20] In addition, evidence suggests that minorities with SMI and diabetes are less likely to be treated than their white counterparts.

Table 33-1. ADA/APA Recommendations for Second-Generation Antipsychotic Medications Metabolic Monitoring[88]

	Baseline	4 weeks	8 weeks	12 weeks	Quarterly	Annually	Every 5 years
Weight (BMI)	X	X	X	X	X		
Waist circumference	X			X		X	
Blood pressure	X			X		X	
Fasting plasma glucose	X			X		X	
Fasting lipid panel	X			X			X[a]

Source: Adapted from Amiel JM, Mangurian CV, Ganguli R, Newcomer JW. Addressing cardiometabolic risk during treatment with antipsychotic medications. Current Opin Psychiatry 2008;21(6):613-618.
[a]Annual lipid panel screening for commonly occurring higher-risk patients (e.g., overweight or obese).

NICOTINE DEPENDENCE

> Ms. Jones has been smoking a pack a day for close to 20 years. She also admits that she used cocaine and other drugs right before her recent psychiatric hospitalization.

Smoking rates among people with SMI are extremely high: close to 59% of people with schizophrenia smoke compared with 18% in the general population.[21] Smoking puts people with SMI at increased risk for CVD and influences recommendations for initiating oral medications for metabolic abnormalities.[22] In a study of 1,213 people with schizophrenia-related psychotic disorders, the odds ratio of cardiac-related death among those aged 35–54 years was increased 12-fold in smokers relative to nonsmokers[22] Unfortunately, smokers with type 2 diabetes and schizophrenia were significantly less likely to receive services and treatments known to improve cardiovascular outcomes (e.g., blood pressure exams, lipid profiles, treatment with angiotensin-converting enzyme inhibitor [ACE] inhibitors or statins) when compared to people with diabetes who did not have SMI regardless of smoking status.[23] Although the exact cause is unknown, this particular health disparity is highly concerning given the proven increased risk of CVD with smoking.

The Schizophrenia Patient Outcomes Research Team (PORT) recommends that people with schizophrenia who want to quit or reduce cigarette smoking be offered treatment with bupropion SR 150 mg twice daily for 10–12 weeks, with or without nicotine replacement therapy, to achieve short-term abstinence.[24] The pharmacological treatment should be accompanied by a smoking cessation education or support group.[24]

Table 33-2. Recommendations to Improve Chronic Illness Outcomes in People with Severe Mental Illness

- Annual screening for diabetes and other metabolic risk factors, regardless of age
- Treat of diabetes and other metabolic risk factors
  - Metformin may be effective in preventing pre-diabetes conversion to frank diabetes and in reversing second-generation antipsychotic (SGAs) medications associated weight gain.[89]
  - People with severe mental illness are receptive to treatment of metabolic disorders when available and adherence to oral hypoglycemic medications is better among diabetes patients with schizophrenia than those people without schizophrenia.[90]
- Consider switching antipsychotic medications:
  - Switching from higher to lower metabolic risk antipsychotics can produce weight and lipid benefits without significant clinical deterioration.[91]
  - Among SGAs, clozapine (Clozaril) and olanzapine (Zyprexa) are highest risk; risperidone (Risperidone) and quetiapine (Seroquel) have intermediate risks; and ziprasidone (Geodon) and aripiprazole (Abilify) have low risk for metabolic problems.[91]
  - A careful risk/benefit assessment should be done with the patient and patients should be informed about what to expect.[91]
  - Gradually discontinue the current medication.[91]

SUBSTANCE ABUSE

Among people with SMI, the Substance Abuse and Mental Health Services Agency (SAMHSA) estimates that 27% have had a co-occurring substance use disorder in the previous year.[6] Of the 2.6 million adults with both a SMI and a co-occurring substance use disorder, 35% received no treatment for either problem and only 20% received treatment for the substance abuse disorder.[6]

SAMHSA has put forth the SBIRT (screening, brief intervention, and referral to treatment) model as a comprehensive integrated public health strategy for dealing with substance abuse in the primary care setting.[25] It involves universal screening, 5–12 brief sessions (5–10 minutes each) targeting risky behaviors, and referral for more comprehensive treatment in patients with very high risk or when dependence criteria are met. The SBIRT model has demonstrated effectiveness for reducing risky alcohol behaviors and there is growing evidence that it is also effective in reducing risky drug use behaviors. Using the SBIRT model is consistent with the Schizophrenia PORT recommendation that people with schizophrenia and a comorbid alcohol or drug use disorder should be offered substance abuse treatment.[24]

HUMAN IMMUNODEFICIENCY VIRUS

> Ms. Jones had traded sex for drugs on a number of occasions.

The prevalence of HIV infection among people with SMI is 6.0% (95% CI 4.3-8.3), which is significantly higher than in the general population (0.6%).[26] The increased prevalence is complex and multifactorial, including higher rates of HIV risk behaviors, lack of knowledge about HIV transmission and prevention, lack of motivation to engage in safer practices, lack of the behavioral skills to engage in prevention practices, and residing in neighborhoods or institutional settings (such as homeless shelters) where HIV is prevalent.[27] Additionally, some psychiatric disorders themselves cause symptoms (e.g., impulsivity, increased sexual activity, poor cognitive function) that contribute to higher HIV risk behaviors.[27,28]

Despite this high prevalence, HIV testing among people with SMI is low.[29] Since African Americans and Latinos have the highest rates of HIV in the general population, this deficiency in HIV testing is likely to be particularly problematic for underserved racial minorities with SMI.[30]

People with SMI should be tested annually for HIV (see Box 33-1) and if infected suppressing their viral load is an important treatment goal. In addition, roughly 25% of people living with HIV are coinfected with hepatitis C virus (HCV) and in those who are intravenous drug users, the coinfection rate is 75%.[31] They should also be screened both for HCV and hepatitis B. If they have not been vaccinated for hepatitis B, they should be.

Regular screening for CVD and treatment of modifiable risk factors such as smoking, obesity, and the metabolic syndrome is also essential. It is important to note that people with HIV alone have high rates of CVD. This is partly due to HIV itself and the fact that traditional CVD risk factors (smoking, dyslipidemia) are highly prevalent in this population.[32] CVD risk in those with HIV is additionally increased due to the side effects of protease inhibitors, the most common front line of treatment for HIV infection, which themselves promote dyslipidemias.[33]

HEPATITIS C

The prevalence of HCV infection among people with SMI is 17.4% (95% CI 13.2-22.6), which is significantly higher than in the general population (1%).[34] Despite the serious health impacts of this disease and the high risk in this population, most patients with SMI are neither tested nor treated (Box 33-1).[35] It is possible that fear of HCV treatment–related psychiatric symptoms, as well as perceived low adherence, has resulted in providers' reluctance to refer and treat people with SMI.[35]

Studies have demonstrated similar adherence and response rates among populations with and without SMI, when done in concert with mental health treatment. Further, the risk of psychiatric symptom exacerbation (e.g., depression, psychosis) due to HCV treatment with interferon may be overstated.[36] That said, these potential exacerbations are important to include in discussions with patients.

Recently, the development of interferon-free, direct-acting antiviral agents is revolutionizing HCV treatment and offering the potential of cure.[37] However, the first such FDA-approved agent, sofosbuvir (Sovaldi) is extremely expensive (~$84,000–$120,000 per patient), which limits the availability of this agent to the general population. The appropriate use of these new agents in patients with SMI is unknown.

Although no screening tool exists specifically for the selection of HCV treatment for people with comorbid SMI, the Beck Depression Inventory (BDI) has been examined in samples of people with depression and suggest that people with baseline scores >10 are more likely to develop interferon-associated depression. For these patients, "pre-treatment" with an antidepressant should be considered and, if initiated, should be continued for the duration of HCV treatment.[38] All things being equal, the selective serotonin reuptake inhibitors (SSRIs), citalopram, and sertraline are good choices for HCV-related depression prevention and treatment due to their equivalent efficacy to other SSRIs, good tolerability, and low drug–drug interaction profiles (see later).[38] One-third of HIV specialists use or offer the option of prophylactic antidepressants to people with comorbid HCV and HIV with no past or current depression, with the number rising to more than two-thirds among people with a history of depression but no current symptoms.[39] Notably, this pretreatment with SSRIs should be avoided in a patient with bipolar disorder or schizoaffective disorder to avoid SSRI-induced mania.

It is advised that prior to initiating interferon-based HCV treatment, the client is at his or her baseline mental health level. Ideally, appropriate patients for treatment are ones who are not actively suicidal, can be closely monitored clinically (weekly or biweekly), and can successfully complete necessary serologic testing. Patient should be monitored at baseline and then monthly during treatment with a clinical interview and Patient Health Questionnaire 9 (PHQ9) screening tool. Since many clients will continue to experience depression despite use of an SSRI during HCV treatment, nonmedication treatments such as supportive therapy are also recommended.[40]

Many psychiatric medications can impair liver function as can both the HCV itself and HCV treatments. Therefore, monitoring of liver enzymes is recommended at baseline, within 1 month of starting treatment, and every 2–3 months during treatment.

PSYCHIATRIC COMORBIDITIES AMONG PEOPLE WITH MEDICAL ILLNESSES

Mr. Smith is a 70-year-old man with diabetes and CVD (i.e., previous myocardial infarction and coronary artery bypass surgery); during a regular visit, he admits to feeling a little "low" recently.

Box 33-3. Mental Health Screening Tools for Primary Care

- Depression: PHQ-9
- Anxiety: generalized anxiety disorder-7 (GAD-7)
- Posttraumatic stress disorder (PTSD): Primary Care-PTSD Screen (PC-PTSD)
- Alcohol abuse: Alcohol Use Disorders Identification Test (AUDIT) or CAGE Substance Use Screening Tool
- Other substance abuse: DAST-10 or ASSIST
- General behavioral health: Patient Stress Questionnaire

More than 80% of primary care patients who have co-occurring mental health disorders are either undertreated or receive no treatment for their mental illness at all.[41,42] This lack of treatment is due, in part, to underdiagnosis.[41] Routine screening in primary care settings could enable earlier identification and treatment of mental health and substance use disorders (Box 33-3). In addition, the US public mental health-care system is designed primarily to treat those with SMIs (e.g., schizophrenia, bipolar disorder). This often leaves safety-net primary care providers holding the responsibility to care for those with less SMIs. This section aims to make recommendations on treatment of common medical conditions in primary care. More ideal models of primary care and behavioral health integration are described in the next section.

MAJOR DEPRESSIVE DISORDER

In primary care, the prevalence of major depressive disorder (MDD) ranges from 5% to 13% in adults and 6% to 9% in older adults.[43] Depression is associated with poorer outcomes among people with a variety of medical conditions, including coronary artery disease, diabetes, and stroke.[44] Treatment of depression may reduce mortality from these conditions, and help prevent suicide.[45] Accurate identification of depression is critical so that appropriate treatment can be initiated.

If clinical practices have systems in place to ensure accurate diagnosis, effective treatment, and follow-up, the US Preventive Services Task Force recommends screening adults for depression.[43] There is some evidence that asking two questions in the PHQ-2 may be as effective as the longer PQH-9.[46] Treatment with antidepressants, psychotherapy, or both decreases clinical morbidity and improves outcomes in adults with depression identified through screening in primary care settings.[43] For people with comorbid anxiety and depression, short-term use of long-acting benzodiazepines is widely accepted until SSRIs begin to exert their antidepressant effects.[47]

ANXIETY DISORDERS

Anxiety disorders affect about 40 million American adults (~18%) annually.[48] They are commonly seen in primary care, affecting about 10% of patients.[49] There are a wide variety of anxiety disorders, including GAD, obsessive-compulsive disorder, panic disorder, PTSD, and social phobia. Unfortunately, people with anxiety disorders are often underdiagnosed and undertreated.[49]

In general, anxiety disorders are treated with medication, specific types of psychotherapy, or both depending on the illness and patient preference.[48] SSRIs are considered first-line therapy in the treatment of various anxiety disorders because of their efficacy, good tolerability, and efficacy for comorbid depression.[47] However, SSRIs have a delayed onset of effect and often anxiety and agitation are associated with initiation. Although benzodiazepines quickly treat anxiety and have few side effects, people can develop tolerance; so benzodiazepines are generally prescribed only during initiation, except for people with panic disorder, who can take benzodiazepines for up to a year without harm.[47] We strongly recommend starting a long-acting benzodiazepine for a short period when initially starting SSRIs for people with anxiety. Using in a scheduled fashion, rather than as needed, helps prevent anxiety attacks rather than waiting for them to occur and then creating a reinforcing and dependence creating scenario.

POSTTRAUMATIC STRESS DISORDER

In primary care settings, the prevalence of PTSD appears to depend upon the population studied.[50] For example, although the US lifetime prevalence of PTSD is around 7%, the rates are higher in Veterans Affairs settings (11–20%) or urban low-income samples (20–30%).[50] Refugees and those exposed to violence or natural disasters also have higher rates of PTSD. Given under-recognition of PTSD in primary care and the high incidence of trauma in safety-net populations, it is important that primary care providers ask about trauma and PTSD symptoms of PTSD.

Screening and treating anxiety and PTSD can alleviate significant suffering. Screening tools such as the GAD-7 and PC-PTSD are particularly useful in practices that draw patients from areas with high rates of trauma, large underserved areas, or care for patients who have immigrated from regions in the world where there has been unrest or political oppression. Treat anxiety disorders with medications (SSRIs), psychotherapy, or both. Because of the risk of increased anxiety when starting an SSRI, strongly consider initiating long-acting benzodiazepines (e.g., clonazepam, lorazepam) and slowly taper after a few weeks. The major exceptions are with PTSD or significant substance use disorder where benzodiazepines should be used with caution or discouraged altogether.

SUBSTANCE ABUSE

> When you ask Mr. Smith to tell you how he has been dealing with his feelings, he reports that he has been drinking more beer than he usually does.

Since the management of alcohol and drug abuse is outlined elsewhere (see Chapter 39), we focus in this section on people with comorbid substance abuse and mental illness. In 2012, almost 20% of people with any mental illness met criteria for a substance use disorder.[6] The adverse health effects of alcohol and other illicit drug use are significant for these already vulnerable patients. The US Preventative Services Task Force does recommend screening adults for alcohol misuse and provide persons engaged in risky or hazardous drinking with brief behavioral counseling interventions.[51] Although the US Preventative Services Task Force does not recommend routine drug screening in primary care, we recommend this screening for people comorbid psychiatric disorders.[52] The SBIRT approach can be implemented for people at risk or with substance use disorders using existing screening tools including the following: Alcohol Use Disorders Identification Test (AUDIT-C) and CAGE for alcohol abuse; and the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) or Drug Abuse Screening Test (DAST-10) for illicit drug abuse.

SUICIDE

> Mr. Smith admits that his wife died the month before this visit. When asked if he has been thinking of suicide, he begins to cry.

Almost 40% of people who commit suicide visit their primary care provider within 1 month before dying, with those rates being even higher for the elderly (50–70%).[53] Although suicide is a rare event, the rates of suicide are much higher among people with depression, bipolar disorder, schizophrenia, anxiety, personality disorders, and alcohol and drug abuse.[54] Therefore, primary care providers play a critical role in screening patients with these psychiatric comorbidities. Many providers are uncomfortable asking about suicide for fear that these questions will actually cause patients to start thinking about suicide. There is no evidence that people start to think about suicide just because someone asks them.[54]

These providers should pay particular attention during periods of high suicide risk, such as immediately after discharge from a psychiatric hospital or an emergency room visit for self-harm.[53] Useful questions include: "Have you ever felt that life was not worth living?" or "Did you ever wish you could go to sleep and just not wake up?" If you have a patient who is acutely suicidal, obtain an emergency psychiatric consultation to conduct a full suicide risk assessment.

Emergency psychiatric consultation should be obtained when encountering an acutely suicidal patient. Although psychiatrists cannot predict who will commit suicide, a thorough suicide risk assessment can reduce or eliminate suicide risk.[54] A psychiatrist uses the suicide risk assessment to identify and treat acute risk factors (e.g., anxiety, insomnia, psychosis, depression, substance abuse), remove access to means (e.g., firearms), and mobilize protective factors.[54] This risk assessment consists of inquiry into specific plans, intent, methods, previous suicide attempts, thoughts or plans of violence to others, psychiatric symptoms, associated substance abuse, acute and chronic stressors, external supports, and any future-oriented planning. Although the psychiatrist will perform this evaluation, any pertinent information obtained from the patient or collateral sources by the medical provider will be helpful to the consultant.

Because the patient has come to their primary care provider for help, that person should remain involved in the initial suicide assessment and management. If the provider flees the office to call the psychiatrist at the first mention of suicide, the patient may interpret this as an indication of the provider's discomfort or disinterest in the issue and cause more anxiety and depression. Because most suicidal patients feel overwhelmed and need support, having their primary care provider spend even a short amount of time with them prior to the arrival of an unfamiliar consultant may be very comforting.

The primary care provider and clinic staff are legally responsible for the patient's safety throughout the evaluation process. This may require that the patient remain in full view of staff members at all times. If the patient wishes to leave the clinic before the suicide risk assessment is complete, he or she should be encouraged to stay and may need to be informed that the staff is obligated to detain him or her in clinic pending a full evaluation. For patients who refuse, and proceed to leave, it is imperative to notify security personnel or police to prevent this from happening. Clinic staff should avoid directly restraining patients. If the patient does leave, police should be notified immediately to ensure the patient's safe return. If there is any admission or suspicion of recent drug overdose, immediate emergency medical evaluation is warranted. At the end of the evaluation process, a detailed account of the reasons for concern and consultation obtained should be entered into the medical record.

THE "DIFFICULT" PATIENT: BORDERLINE PERSONALITY DISORDER

Borderline personality disorder (BPD) is a serious and chronic mental illness with 80% of these patients having

suicidal behaviors, and 4–9% committing suicide.[55,56] The disorder is characterized by an intense fear of abandonment, labile moods, impulsivity, and unstable relationships. About 85% of people with BPD have co-occurring psychiatric disorders, most commonly depression, anxiety, eating disorders, and/or substance abuse.[55] Unfortunately, BPD is often underdiagnosed or misdiagnosed.[56] A mental health clinician can diagnose borderline personality with a psychiatric interview and collateral information. Evidence supports psychotherapy, particularly dialectical behavioral therapy, as the primary treatment with adjunctive psychotropic medications based upon symptoms.[55]

People with BPD commonly have other medical conditions such as diabetes, high blood pressure, chronic back pain, arthritis, and fibromyalgia.[55,56] Unfortunately, because of their psychiatric illness, people with BPD are often viewed as being "really difficult" patients. This impedes good clinical care. Although psychotherapy is out of their scope of practice, a primary care provider can serve an important role by establishing themselves as a reliable, predictable clinician who values the patient's health.[56]

Some keys to working with these patients include (1) limit setting and maintaining boundaries, (2) acknowledging and empathizing with their intense feelings and unstable moods, and (3) providing consistency.[55,56] The limit setting should be discussed explicitly early in the course of treatment before problems arise. For example, primary care providers should make clear limits on the frequency and length of phone calls or emails these patients exchange with the clinic. It should be clear that these are clinic policies that all patients have to follow, and the potential repercussions of not following these should also be clear. Although maintaining limits is difficult when treating these patients, making exceptions is strongly discouraged. Brief, structured, and frequent office visits can be helpful for some of these patients.

While empathizing with the feelings of a borderline patient is important, it is equally as important to try to avoid responding to provocations and remain emotionally neutral. In addition, coordination of care with mental health providers and other coworkers is helpful to avoid splitting (e.g., idealizing one provider while devaluing another) and to provide consistency. Furthermore, it is helpful for team members to meet periodically to ensure consistency of responses to patient behaviors and provide peer support.

Often, the patient with BPD may "fire" their provider because of accusations of inadequate and/or incompetent care. If the provider remains consistent and empathetic, many of these patients will return to treatment. It is important that the primary care provider keep in mind that these behaviors are symptoms of the patient's illness, not any indication of their own abilities as a provider. Moreover, it can be helpful for providers to discuss their own feelings with each other in an effort to contain these feelings themselves.

PSYCHIATRIC COMORBIDITIES AMONG PEOPLE WITH HIV

> Mr. Rodriguez is a 45-year-old Latino homeless man who has been living with HIV for the past 15 years. He has had variable adherence to the medication regimen prescribed. He presents with low energy, lack of appetite, and poor sleep that he attributes to his medications. He appears more withdrawn than he has been in the past.

Psychiatric and substance use disorders are markedly more common among people infected with HIV than among the general population.[32,57] From early in the epidemic, the most effective HIV care has been accomplished in multidisciplinary HIV clinics that took seriously the nonprimary medical issues of the patient.[58] However, over time, due to an expanding epidemic and marked improvements in HIV treatments making HIV infection a "chronic disease," primary care providers have taken up the task of treating these medically and psychosocially complex patients.[59,60]

Given the high rates of comorbid conditions among those with HIV, primary care providers who care for those with HIV need to be prepared to care not only for those with HIV infection but also those who are commonly referred to as "dually" or "triply diagnosed" (e.g., those with HIV infection, a mental health disorder, and/or a substance use disorder). To provide this care, primary care providers need to be willing to talk to patients about the larger contextual issues that are common in patients with HIV. These include common psychosocial stressors of living with a chronic illness, as well as other more specific stressors associated with HIV. For example, these people struggle with stigma, discrimination, living as an HIV-infected person, issues of disclosure, questions of fertility and possible parenthood, waxing and waning health, and the struggle of taking a variety of medications for the "rest of one's life." Any and all of these can be difficult outright and can complicate the treatment of HIV infection as patients cope with these psychosocial issues.

Appropriate diagnosis and treatment of psychiatric disorders in people with HIV is a critical component of HIV care. Successful treatment of such disorders has multiple positive effects including overall improved health, heightened quality of life, and improved compliance with taking antiretroviral drugs which, in turn, slows the progression of HIV infection and prevents other medical complications from developing.[32] Of particular note

is that the most effective treatment for HIV-associated dementia (HAD) is an undetectable viral load, which is only accomplished by good adherence to antiretroviral regimens.[32]

MAJOR DEPRESSIVE DISORDER

> After completing the full PHQ-9, you find that Mr. Rodriguez fulfills criteria for a major depressive episode. You are considering an SSRI, but are worried about side effects with his HIV medications.

MDD is the most common psychiatric diagnosis among people living with HIV/AIDS, with estimated rates three times that of the general population.[61] There is no clearly preferred medication for MDD in HIV patients. Some concerns about SSRIs and protease inhibitors and non-nucleoside reverse transcriptase inhibitors affecting the activity of the cytochrome P450 (CYP450) izoenzymes,[62] though this interaction is thought to be generally quite small.[63] It is recommended to start low and raise doses in small increments—being particularly careful with patients treated with ritonavir, efavirenz, or saquinavir.

Studies have also shown serotonin–norepinephrine reuptake inhibitors to be successful as first-line therapies. One study showed that venlafaxine has a small effect on cytochrome P450, decreasing the potential interaction with antiretroviral drugs, though this does not recommend dosage changes.[64] Bupropion and nefazodone are second-line choices. These medications have also been used with success, though dose adjustments of bupropion are needed when used in combination with lopinavir/ritonavir due to induction of the enzymes CYP2B6 and the UDP glucuronosyl-transferase which reduce bupropion levels.[65]

ANXIETY DISORDERS

Anxiety disorders are commonly diagnosed in people with HIV.[66] While SSRIs are commonly prescribed to treat anxiety, benzodiazepines are prescribed as well and account for 66.3% of all anxiolytics prescribed to HIV-infected patients.[66] That said, significant interactions have been reported between antiretroviral drugs and benzodiazepines. For instance, due to its inhibitory effects on the CYP3A isoenzyme, low doses of ritonavir can significantly impair the clearance of alprazolam (Xanax).[66]

BIPOLAR DISORDER

People with HIV are significantly more likely to have bipolar disorder than the general population.[67] In addition, people with comorbid HIV and bipolar disorder are more likely to engage in high-risk behaviors and have poor rates of adherence to HIV medications.[67] As such, it is critical to treat their underlying bipolar disorder to improve overall HIV care among this population.

Lithium is commonly used in the treatment of bipolar disorders in HIV/AIDS patients on antiretroviral therapy (ART) because it does not have any known interactions. In addition, lithium does not appear to influence the course of HIV infection.[68] Evidence indicates that valproic acid does not affect viral load among HIV patients receiving adequate ART.[69] People taking zidovudine should be monitored for zidovudine toxicity because valproic acid is an inhibitor of glucuronidation. Lamotrigine (Lamictal) is effective and well tolerated among people with Type II bipolar disorder or refractory MDD. Since the antiretroviral drugs, lopinavir and ritonavir, decrease lamotrigine plasma levels, dose adjustments must be considered in patients receiving these medications.[70] It is also notable that lamotrigine has been found to be a successful treatment for HIV-associated neuropathic pain.[71]

PSYCHOTIC DISORDERS

Because of the significant prevalence of HIV disease among people with SMI, the use of antipsychotic medication is infrequent. Because of subcortical slowing associated with HIV infection of the central nervous system, HIV-infected patients may be more sensitive to extrapyramidal effects of antipsychotic medications and lower starting doses and slower titration is recommended. In addition, because of the risk of developing dislipidemias and hyperglycemia in HIV-infected patients receiving ART, this must be considered when prescribing SGAs—especially those that increase metabolic risk.[10,72] Further, in a recent study of people receiving both ART and SGAs medications, the use of SGAs in HIV-infected individuals increased the risk of hyperlipidemia, hypertension, and diabetes over uninfected patients receiving SGAs.[72]

HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS

Neurocognitive symptoms have been a well-known clinical phenomenon of HIV disease from the early days of the epidemic Initially termed "HIV encepalopathy" to describe acute mental status changes or "AIDS Dementia" to designate the more indolent, chronic, and progressive form, characterized by clinically symptomatic presentations of decreased memory, difficulty concentrating, poor attention, psychomotor retardation and poor fine muscle skills. The progressive spectrum of the disorders are now recognized by the term "HAND" (HIV-associated neurocognitive disorders). HAND describes the range

of progressive central nervous system (CNS) involvement from asymptomatic neurocognitive impairment and mild neurocognitive disorder to the most severe forms of dementia.[73]

ART has been shown to lead to improvement in HAND-associated neurocognitive deficits, with the greatest improvement seen among those who attain complete suppression of cerebral spinal fluid (CSF) viral load.[72] Thus, the primary goal of ART in HAND is to produce complete virological suppression in plasma and the CNS. Combination regimens are now the standard treatment for patients with HAND.

SMOKING, ALCOHOL ABUSE, AND OTHER DRUG ABUSE

> Mr. Rodriguez has bruising on his arms. When asked about these bruises, Mr. Rodriguez admits that he has been injecting crack cocaine because of his low energy.

Smoking—More than half of people with HIV are smokers, and those who smoke have greater morbidity and mortality than those with HIV who do not smoke.[32] As many as two-thirds are interested in quitting when asked, and nicotine replacement therapy should be strongly encouraged.[74] Screening for smoking should be routine. Nicotine replacement therapy and smoking cessation courses should be offered to all people with HIV who are interested in stopping smoking.

Alcohol abuse—Alcohol use is also frequent among people with HIV. More than half (53%) of people receiving care for HIV reported drinking alcohol.[32] Among those who consumed alcohol, 15% were heavy drinkers, a rate twice that of the general population.[32] Heavy drinking was significantly higher among users of cocaine or heroin and significantly lower among the better educated and those with AIDS.[75]

Other drug abuse—People living with HIV also have high levels of other drug abuse.[57] Nearly 40% reported using an illicit drug other than marijuana (e.g., sedatives, amphetamines, analgesics, cocaine, inhalants, lysergic acid diethylamide or hallucinogens, or heroin) in the previous 12 months. More than 12% screened positive for drug dependence during the previous 12 months.[57] Given these high rates of comorbidity, it is recommended that all people with HIV should get screened (and referred if needed) for smoking and substance abuse.

Given the multiple vulnerabilities for these patients outlined earlier, research has looked at various ways to improve adherence to care for people with HIV in primary care settings. These activities were found to be relatively low cost, but high yield (Box 33-4).

Box 33-4. Overall Recommendations: Management of Psychiatric Comorbidities among People with HIV

- Provide brochures, posters, and other written messages to patients emphasizing the importance of attendance at clinic visits.[76]
- Provide enhanced personal contact with HIV patients to improve attendance and rate of keeping appointments (e.g., brief face-to-face meeting upon returning for care visit, interim visit call, appointment reminder calls, missed visit calls).[76]
- Obtain local AIDS social service and support group information (1-800-CDC INFO or 1-800-232-4636) which offers information and local referrals, 24 hours a day, 7 days a week. Most of these services are free of charge and may offer a range of social support, housing, and other services.
- Emphasize the importance of adherence to antiretroviral medications.
- Develop a relationship with an AIDS knowledgeable psychiatrist.

MODELS OF HEALTH-CARE INTEGRATION

> Mr. Daniels is a 52-year-old man who has been coming several times a week to his community mental health clinic for the past 8 years. He likes his clinic because he has socialization with his peers and attends several groups. He has a diagnosis of schizoaffective disorder and has averaged two psychiatric hospitalizations a year. He takes a mood stabilizer and an antipsychotic medication and has developed the metabolic syndrome. Recently, he has been feeling more short of breath and fatigued with some lower extremity swelling. He has never had a primary care doctor.

Many models of integration of primary care and behavioral health have been proposed.[77-79] The SAMHSA-HRSA Center for Integrated Health Solutions developed a framework to distinguish levels of collaboration and integration, specifically minimal collaboration, basic collaboration at a distance, basic collaboration onsite, close collaboration onsite with some system integration, close collaboration approaching an integrated practice, and full collaboration in transformed/merged integrated practice (Table 33-3).[80] There are key clinical delivery, patient experience, practice organization, and business model factors that differentiate these levels, with advantages and disadvantages to each.[80] Having this framework is very useful for public health administrators as they aim for better integration.

Table 33-3. Six Levels of Collaboration between Behavioral Health and Medical Care[80]

Coordinated **Key Element: Communication**		**Co-located** **Key Element: Physical Proximity**		**Integrated** **Key Element: Practice Change**	
Level 1 Minimal Collaboration	**Level 2** Basic Collaboration at a Distance	**Level 3** Basic Collaboration Onsite	**Level 4** Close Collaboration Onsite with Some System Integration	**Level 5** Close Collaboration Approaching an Integrated Practice	**Level 6** Full Collaboration in a Transformed/ Merged Integrated Practice
Behavioral health, primary care, and other health-care providers work					
In separate facilities, where they:	In separate facilities, where they:	In same facility not necessarily same offices, where they:	In same space within the same facility, where they:	In same space within the same facility (some shared space), where they:	In same space within the same facility, sharing all practice space, where they:
Have separate systems	Have separate systems	Have separate systems	Share some systems, like scheduling or medical records	Actively seek system solutions together or develop work-a-rounds	Have resolved most or all system issues, functioning as one integrated system
Communicate about cases only rarely and under compelling circumstances	Communicate periodically about shared patients	Communicate regularly about patients, by phone or e-mail	Communicate in person as needed	Communicate frequently in person	Communicate consistently at the system, team, and individual levels
Communicate, driven by provider need	Communicate, driven by specific patient issues	Collaborate, driven by need for each other's services and more reliable referral	Collaborate, driven by need for consultation and coordinated plans for difficult patients	Collaborate, driven by desire to be a member of the care team	Collaborate, driven by shared concept of team care
May never meet in person	May meet as part of larger community	Meet occasionally to discuss cases due to close proximity	Have regular face-to-face interactions about some patients	Have regular team meetings to discuss overall patient care and specific patient issues	Have formal and informal meetings to support integrated model of care
Have limited understanding of each other's roles	Appreciate each other's roles as resources	Feel part of a larger yet nonformal team	Have a basic understanding of roles and culture	Have an in-depth understanding of roles and culture	Have roles and cultures that blur or blend

Source: From Heath B, Wise Romero P, Reynolds K. A Review and Proposed Standard Framework for Levels of Integrated Healthcare. Washington, DC: SAMHSA-HRSA Center for Integrated Health Solutions, March 2013.

INTERVENTIONS TO IMPROVE PRIMARY CARE AND BEHAVIORAL HEALTH INTEGRATION

A number of studies trying to determine critical elements of integration of behavioral health care into the primary care setting have been attempted. A meta-analysis of these studies suggests that the most effective model is the Collaborative Chronic Care Model (CCM), which appears to improve both mental and physical quality-of-life outcomes.[81] Evidence shows that a psychiatrist is a vital part of the CCM collaborative team. The four main elements of the model are as follows[81]: (1) patient self-management support, (2) clinical information systems, (3) system redesign, and (4) provider decision support.

Two large randomized control trials incorporated CCM elements, and have had successful outcomes by targeting specific clinical populations, tracking objective clinical data, and providing enhanced access to care in a stepped care disease management program as necessary.[82,83] One trial targeted depressed older adults cared for at primary care clinics across the country.[82] Patients were assigned to health-care workers called "depression care managers," who tracked patients' depression scores via PHQ-9. In concert with the primary care physician and consulting psychiatrist, the care managers were able to assist patients in accessing varying levels of support based upon the objective data they collected. This approach both doubled the effectiveness of depression treatment for older adults in primary care, and proved to be a cost-effective strategy.[82] In another trial, patients with SMI in community mental health settings were randomly assigned to a care coordinator who provided health education, medical care coordination, and communication with the primary care practitioner.[83] This is one of the few interventions targeting people with SMI and it resulted in improvements in the number of patients who had a primary care physician, receipt of recommended preventative and cardiometabolic care, and client-rated behavioral health status.[83]

COMMUNITY MENTAL HEALTH CLINIC AS THE PRIMARY CARE MEDICAL HOME

The primary care medical home (PCMH) has emerged as a leading model of integrated care in general.[84] Central aspects of the PCMH model include electronic medical record sharing, care coordination activities, a client-centered focus, enhanced access to care, population management via empanelment, and novel payment models designed to increase reimbursement for non–procedure-based preventative care. The federal government has designated substantial funding for federally qualified health centers to further develop and implement aspects of this model across the country targeting improvement in health care for our most vulnerable segments of society, such as people with mental illness.

In 2002, the four-quadrant model was developed as a framework to determine where care should be received based upon behavioral health and physical health complexity of groups of patients.[78] Since people with SMI are primarily served in community mental health clinics and they have so many medical comorbidities, the four-quadrant model suggests that it is worth considering whether the community mental health clinics should become the PCMH for these patients.[85] In addition to coordinated case management and improving primary care access, community mental health clinics are also well positioned to incorporate evidence-based programs to improve the overall health of people with SMI. Examples of these programs include access to supportive housing, smoking cessation treatment, and health promotion efforts targeting diet and exercise.[24,86] Owing to the high rate of homelessness and marginal housing in this population, assistance with supplemental security income in combination with a supportive employment program is necessary.[87] If not treated in a community mental health clinic, primary care providers should make concerted effort to assist their patients in these domains of care. Figure 33-1 illustrates a proposed hierarchy of care for this vulnerable population to ensure good health.

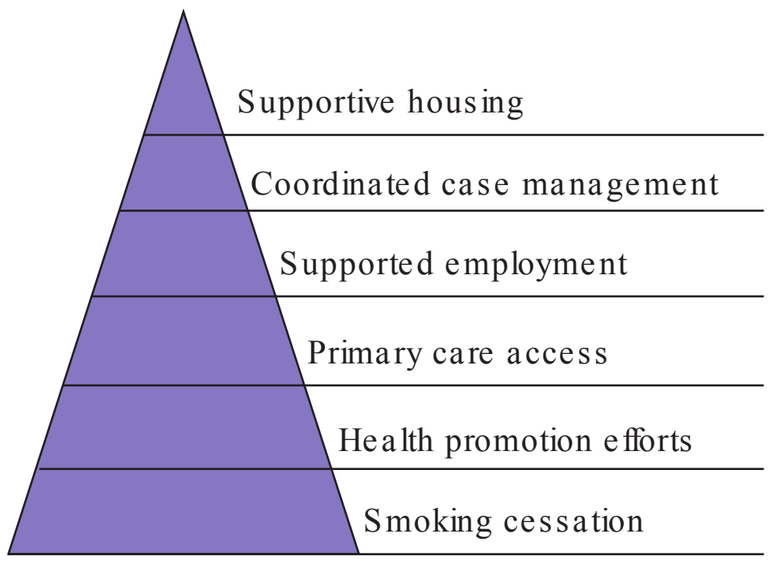


Figure 33-1. Building blocks of health care for people with severe mental illness.

- Screen for mental illness and substance abuse.
- Assess for suicide among people with psychiatric disorders.
- Screen for medical disorders in people with severe mental illness.
- Treat medical illnesses among people with comorbid psychiatric disorders.
- Set clear limits for patients with BPD.
- Screen for mental illness and substance abuse among people living with HIV/AIDS.
- Screen for HIV and hepatitis C in patients with severe mental illness.
- Work to improve primary care and behavioral health integration at your clinic.

Working with People with Psychiatric Illnesses in Primary Care

Do

- Listen.
- Empathize with the struggles of living with a psychiatric illness.
- Empathize with how challenging it is for people to take psychotropic medications.
- Ask about suicide and prior history of physical or sexual abuse.
- Connect them with a mental health provider and establish a collaborative relationship with that person.
- Consider care management for frequent check-ins and facilitation of medical visits for people with SMI.
- Consider team-based care in concert with behavioral health clinicians.
- Consider care management for frequent check-ins and facilitation of medical visits.
- Consider team-based care in concert with behavioral health clinicians.

Don't

- Worry that if you ask about how people feel, you will open a big can of worms. Often, people are quite reassured by just a few minutes of empathic listening.
- Stigmatize people with mental illness or substance abuse.
- Avoid screening for suicide because you are concerned you might put the idea in your patients' head.
- Fail to screen for common and preventable medical illnesses because you think people with mental illness "already have too much going on in their lives."
- Fail to prescribe because you think that people with mental illnesses "will not take the medications anyway."

DISCUSSION QUESTIONS

1. What makes people with mental illness a vulnerable population?
2. What medical conditions should primary care providers screen for among people with SMI?
3. What psychiatric disorders should primary care providers screen for in their clinic?
4. How could your clinic be changed to facilitate better integration of primary and behavioral health care?

RESOURCES

American Psychiatric Association (APA). The APA practice guidelines provide evidence-based recommendations for the assessment and treatment of common psychiatric disorders. http://psychiatryonline.org/guidelines.aspx.

National Institute of Mental Health (NIMH). The NIMH Web site offers mental health information on a variety of psychiatric conditions. http://www.nimh.nih.gov/health/topics/index.shtml.

Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA provides screening tools for a variety of psychiatric and substance abuse disorders. http://www.integration.samhsa.gov/clinical-practice/screening-tools.

National Education Alliance for Borderline Personality Disorder (NEA.BPD). NEA.BPD provides information about borderline personality disorder for patients and professionals. www.borderlinepersonalitydisorder.com.

AIDS Education and Training Center (AETC). The New York and New Jersey AETC provides targeted, multidisciplinary education and training programs for health-care providers treating persons living with HIV/AIDS, including this useful publication: "Psychiatric Medications and HIV Antiretrovirals: A Drug Interaction Guide for Clinicians." http://www.nynjaetc.org/documents/2013_PsychGuide_WEB.pdf.

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Chapter 34

Women's Health: Reproduction and Beyond in Poor Women

Elizabeth Harleman, MD, Carolyn Payne, MD, and Jody Steinauer, MD, MAS

Objectives

- Identify economic, social, and political causes of women's health vulnerability.
- Describe the increased burden of disease for women.
- Review barriers to preventing unintended pregnancy.
- Discuss innovative models for providing care to women.
- Summarize strategies to help women use contraception successfully.

Ellen Reed is a 37-year-old woman with diabetes. She has three children and works two part-time jobs. Though she has health insurance coverage, she has difficulties navigating the system. The financial burden of paying for her many medicines is also prohibitive. Some months she has to forgo medications in order to pay for essentials for her family, like food and rent.

INTRODUCTION

A woman's health and social position are intimately entwined. Social inequalities shape women's illnesses and their options for medical care. Poor women, women of color, and elderly women are particularly affected by social disparities and their consequent impact on health.

Compared with men, women on average possess less social and economic power, are more limited in pursuing higher education and employment opportunities, and shoulder a higher burden of unpaid and hidden work (especially related to family care and community activities). In addition, women are more likely to work in low-wage, high-stress positions in the service industry. All of these inequalities increase women's vulnerability to poverty.

Poverty, in turn, undermines health. Poor women are at increased risk for acquiring disease and have poorer health in general compared with women with greater economic power. Reproductive health in particular suffers in poverty. Women living in poverty are more likely to acquire sexually transmitted diseases and human immunodeficiency virus (HIV). In some regions of the world, complications of pregnancy and childbirth claim the lives or well-being of a significant number of young women. Complications from disease progression (e.g., infertility secondary to untreated pelvic infection) are more prevalent for poor women who experience difficulties accessing health care. Additionally, because many poor women rely on government insurance for reproductive health care, poor women are most directly affected by the politicization of reproductive health care.

This chapter discusses factors that influence and contribute to women's vulnerability, especially as it relates to their reproductive health. It concludes by offering strategies for improving reproductive health disparities with a focus on the United States. Issues related to lesbian health are discussed in Chapter 32.

WOMEN'S HEALTH: WHY ARE WOMEN VULNERABLE?

Women in the United States have a life expectancy of 5 years longer than men and lower age-adjusted death rates than men for 12 of the 15 leading causes of death.[1] However, many women's health needs are inadequately addressed.

COMPETING PRIORITIES

> Ellen is the sole breadwinner and caregiver for her family. Although she knows eating right and exercising are good for her health, she often lacks the time and energy to do either. She even finds it difficult to make time for appointments with her physician.

Women's multiple roles in the family and workplace can make it difficult for them to prioritize their own healthcare needs. Nearly one half (48%) of women aged 18–64 years in the United States have children younger than 18 years at home. Mothers bear a disproportionate burden of responsibility for housework, even if they also work outside the home, as more than two-thirds of them do.[2] The majority of women with young children have primary responsibility for coordinating their children's health care and missing work to care for a sick child. Low-income women are particularly affected by these multiple responsibilities.[2]

In addition to caring for young children, women are often called on to care for elderly or ill parents. These women are likely to have children of their own, work outside the home, and report the presence of a chronic disease themselves. Despite their own need for health care, up to 25% of women caring for elderly, disabled, or ill family members are uninsured. A stark example of how women's health is threatened by their care-taking role was evident in the Ebola outbreak in West Africa, where women, as the care takers of sick family members, were disproportionately becoming infected and dying.

POVERTY

> Last year, Ellen's combined income from her two part-time jobs was $39,500 (the poverty level for a family of four is $23,850). She barely had enough money to purchase all the resources her family required to live and she never had any discretionary income.

In 2012, 15% of families in the United States, almost 46.5 million families, were considered poor. Of all family groups, poverty is highest among those headed by single women. In 2012, 30.9% of all female-headed families (4.8 million families) were poor, compared with 6.3% of married-couple families (3.7 million families).[3] These figures are even more dismaying for women of color, with 51% of Latinos and 49% of African American female-headed households falling below the poverty line, compared with 39% of whites.[4] Women experience increased rates of poverty compared with men throughout their lifespan. Even among the elderly, 13% of women over the age of 75 live in poverty, compared with 6% of men.[5] Individually, women within families may also have less control over financial decisions.

Poverty influences women's subjective and objective health experiences. Poorer women have worse self-rated health status and higher rates of many chronic illnesses, including arthritis, asthma, depression, diabetes, hypertension, obesity, and osteoporosis.[6]

LACK OF HEALTH INSURANCE COVERAGE

Women are more likely than men to be uninsured. In 2012, one-fifth of the US female population lacked health insurance. People without health insurance are more likely to postpone or forgo health care altogether. Women lack health insurance for a variety of reasons, but frequent reasons include Medicaid/Medicare (public insurance programs for the poor, sick, or elderly) ineligibility, lack of access to employer-sponsored programs, and inability to pay for health insurance (Figure 34-1). Historically,

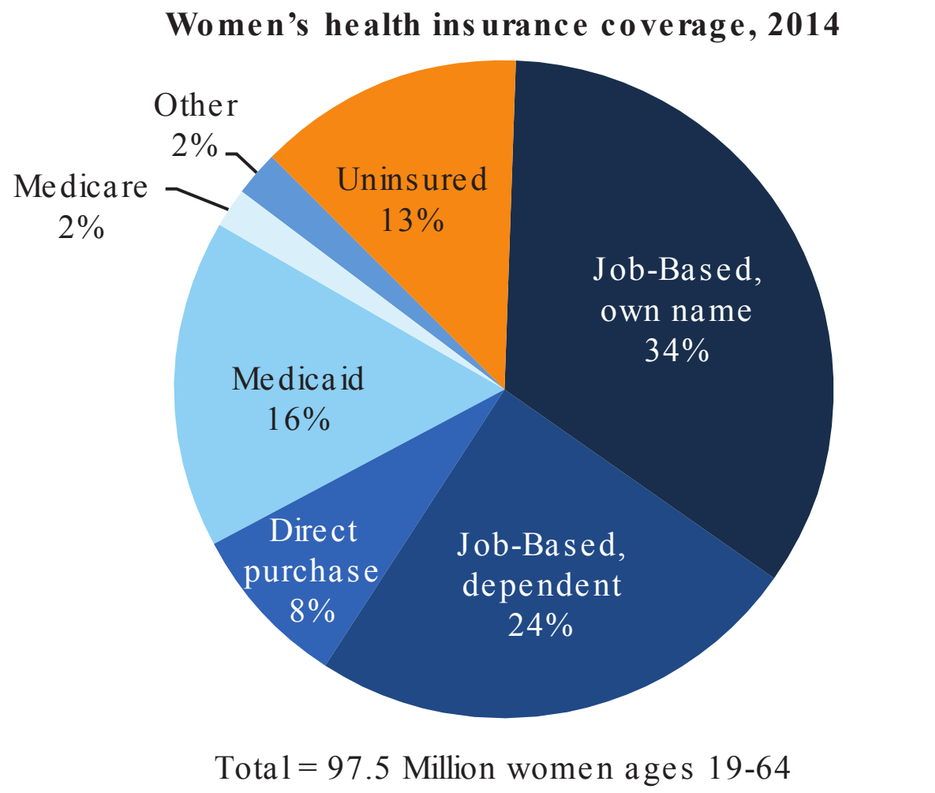


Figure 34-1. Health insurance coverage of women age 19 to 64. (Data from Women's health insurance coverage fact sheet, Nov. 2015 Menlo Park, CA: The Henry J. Kaiser Family Foundation. Accessed December 29, 2014. Available at http://kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/.)

NOTE: For non-elderly women, "other" includes women who are covered through the military or are covered by private insurance for which the origin is unknown. Percentages may not add up to 100% due to rounding.

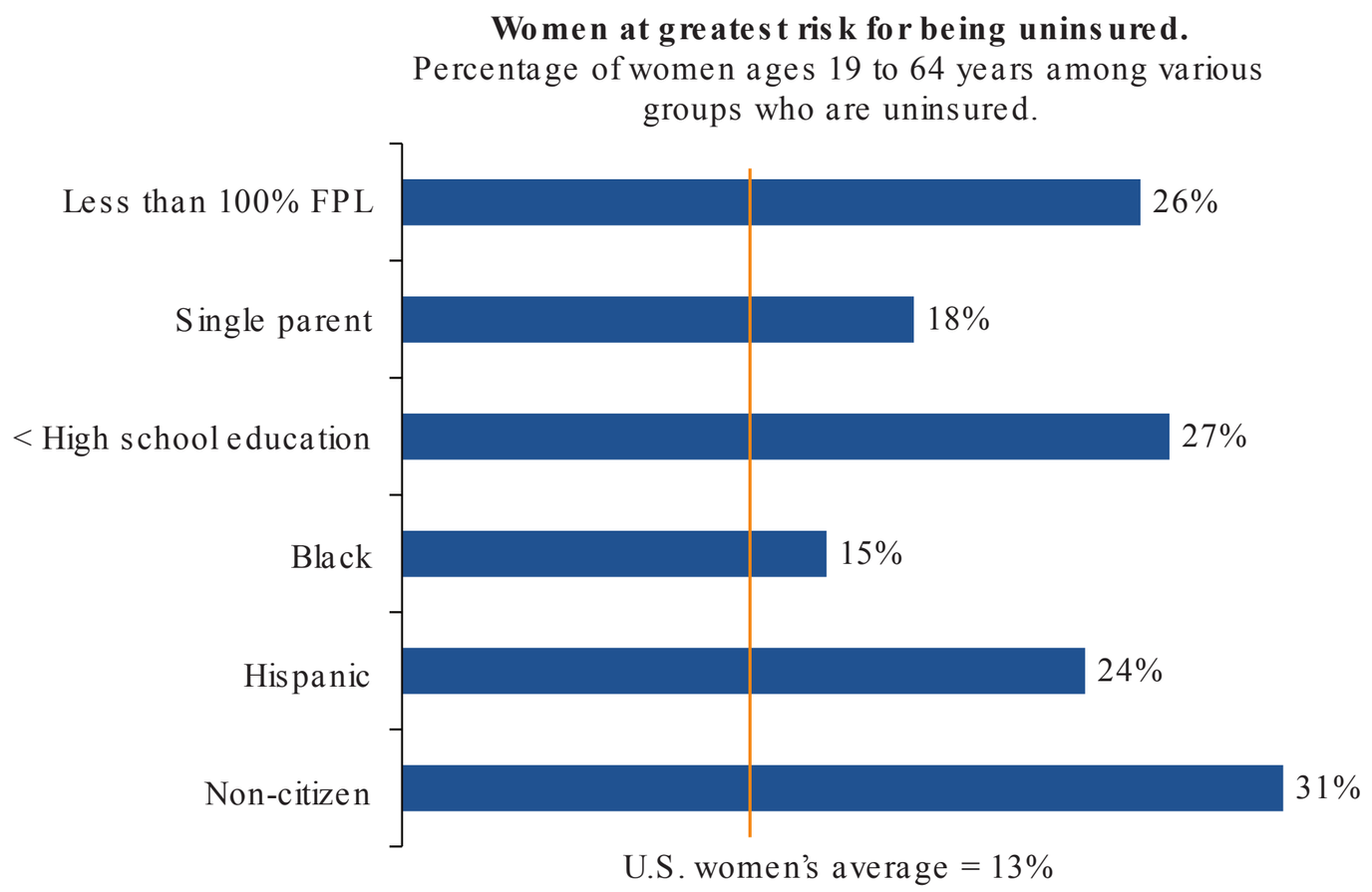


Figure 34-2. Women at greatest risk of being uninsured. Women who are poor, single parents, women of color, who lack education, and non-citizen are at risk for being uninsured. The federal poverty level (FPL) was $19,790 in 2014 for a family of three. (Data from Women's health insurance coverage fact sheet, Nov. 2015 Menlo Park, CA: The Henry J. Kaiser Family Foundation. Accessed Dec. 29, 2015. Available at: http://kff.org/womens-health-policy/fact-sheet/womens-health-insurance-coverage-fact-sheet/.)

women comprised up to two-thirds of the Medicaid population, but have only been eligible for Medicaid if they are extremely poor or pregnant. If women did not fit into these categories, they were unable to qualify for Medicaid no matter how sick they were, or how much of a financial burden accessing care imposed. Medicaid is extremely important to women and children in the United States. Currently, Medicaid finances nearly half of all births in the United States (44.9%), and supports 75% of all publicly funded family planning services.[7,8]

The Affordable Care Act of 2010 has expanded the numbers of people who qualify for Medicaid, by increasing the minimum income requirement to 133% of the federal poverty level and eliminating qualifying conditions. Nevertheless, many states have not expanded Medicaid eligibility, despite the offer of federal funds for the expansion. This decision is projected to result in 2.4 million women being denied Medicaid who would otherwise have received coverage.[9] In addition, for those who will qualify for expanded health insurance coverage, controversy still exists over provision of essential women's health services such as contraception.

Women all over the world perform the majority of unpaid caregiving and uncompensated domestic chores, labor that often does not qualify for benefits and retirement support (and thus may incur risks beyond financial ones). For women participating in the paid labor force, many are low-wage workers in industries that expose them to risk of physical injury and do not offer benefits. In the United States, female sex, younger age, less education, and non-Caucasian ethnicity are risk factors for low-wage employment, poverty, and lack of health insurance coverage.[10] Indeed gender, race, socioeconomic status (SES), and health status are intimately intertwined (Figure 34-2).

Uninsured women are more likely than insured women to postpone medical care, forego prescription medications, and delay or postpone important preventive care such as mammograms and Pap smears (Figure 34-3).[10] They have more limited contraceptive options and the most efficacious forms of contraception are often cost prohibitive without insurance. When they become pregnant, women without insurance are less likely to receive prenatal care, and are at increased risk for poorer maternal and infant health outcomes. Women without insurance have poorer health outcomes in general compared with women with insurance. They are more likely to suffer from uncontrolled chronic medical conditions, and are more likely to die from cancers including breast and cervical cancer.[6] Adequate health insurance coverage is necessary, but alone is insufficient for helping women achieve optimal health outcomes.

UNCOORDINATED SERVICES

A variety of medical specialties attend to the health needs of women across their lifespan. Young women tend to identify generalists or obstetricians and gynecologists (ob-gyns) as their primary care providers, whereas older women are more likely to visit family physicians or internists. The care of women's reproductive system is often separated from the care and management of women's

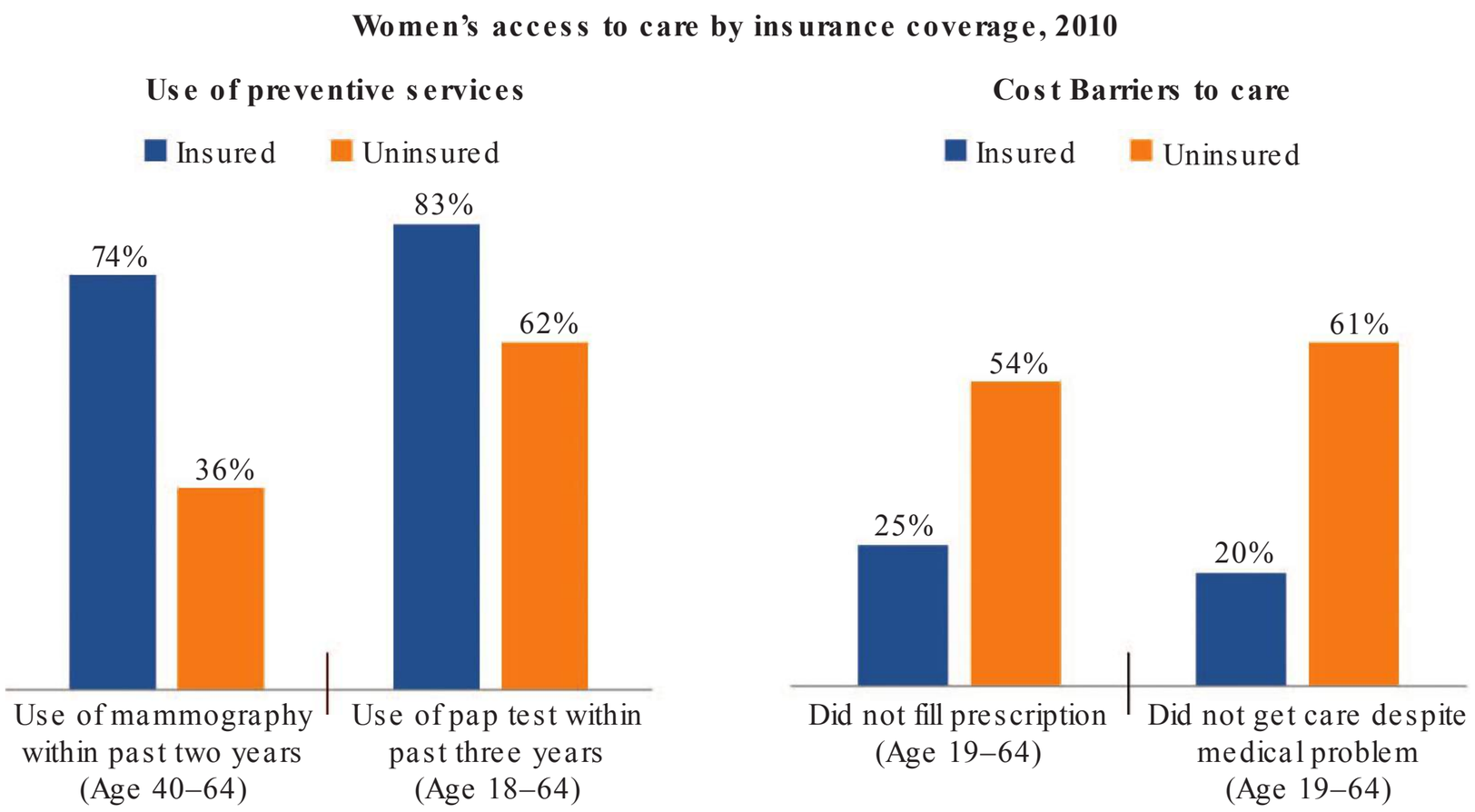


Figure 34-3. "Barriers to health care based on insurance coverage." The uninsured were significantly different from the insured on all measures at $p < 0.05$. (Data redrawn from Women's health insurance coverage fact sheet, November 2013 Menlo Park, CA: The Henry J. Kaiser Family Foundation. Accessed September 2, 2014. Women's Health Policy Facts November 2013. Available at http://kaiserfamilyfoundation.files.wordpress.com/2013/11/6000-11-womens-health-insurance-coverage-factsheet1.pdf.)

other health conditions, creating an imperative to establish relationships with multiple providers, or accept that some aspects of care may not be adequately addressed. This fragmented care is more common in women with limited insurance coverage.

Just as ob-gyns may fail to screen for hypertension or diabetes, other providers caring for women with chronic illnesses may fail to consider women's reproductive lives in the management of their patients' medical conditions. Without considering women's reproductive lives, providers may inadvertently prescribe medications that affect the metabolism of contraception, or are teratogenic. Providers less familiar with reproductive health may also find it difficult to answer women's basic questions about pregnancy options and abortion care services. In addition, the compartmentalization of women's health care needs among specialties, and shortage of primary care physicians in general, may result in neglect of certain areas that do not have a clearly defined "home," such as domestic violence and eating disorders.[6]

RACIAL AND ETHNIC DISPARITIES

Racial and ethnic differences in mortality and health status are observed among women. Women of color are strikingly affected by poorer health outcomes throughout their lives compared to white women. Much of this risk is attributable to the effects of poverty on health, but a differential persists after controlling for income, suggesting that race and social inequality are independent predictors of women's health status. African-American women have more complications of pregnancy and are also at higher risk for chronic illness.[6] African-American and Latina women also suffer more than white women from diabetes and overall poor quality of health.[6] Despite this higher burden of disease, women of color and poor women receive fewer preventive services and screening tests than white women, and are also less likely to be offered important health-care interventions.[11,12] This results in higher mortality for African-American and poor women suffering from medical conditions including heart disease, cancer, and stroke.

VIOLENCE

Violence against women is alarmingly common. With epidemic proportions, it is a major public health and human rights issue. About 35% of women worldwide have experienced either intimate partner violence or nonpartner sexual violence in their lifetime. Low education, experiencing family violence as a child, and attitudes accepting violence and gender inequality are all risk factors for victimization. Political upheaval and displacement increase the rates of violence against women.[13] In the United States, it is estimated that one in four women will experience domestic violence in their lifetime, and 1.3 million women are victims of intimate partner violence each year.[14] Sexual assault is also common. Studies estimate that up to one in six women have experienced an attempted or completed rape.[14] Women who have been involved in prostitution are at particularly high risk for emotional, sexual, and physical violence, but this risk factor rarely becomes known in

the clinical encounter.[15] Women who are the victims of violence also face high rates of physical and mental illness, including HIV (see Chapters 35, 36, and 43). Screening for intimate partner violence and referring to support services for women who are affected is an important part of the clinician's role in addressing this issue.

ATTITUDES

Both women patients and their providers may harbor negative stereotypes that can hinder good care. Women patients may feel reluctant to report symptoms for fear of being thought of as "hypochondriacs." When discussing sexual and reproductive health, women and their providers may feel embarrassed to discuss sexual practices or behaviors. Because taking a complete medical history is important for accurately diagnosing and treating diseases, it is important for health-care providers to create a judgment-free environment in the clinical setting.

Providers bring their own stereotypes about women patients to their interactions. Physicians may be more likely to see women patients as making excessive demands on their time, having complaints influenced by emotional factors, or having a psychosomatic component to their illness.[16] These gender stereotypes can influence clinical care. Women tend to receive more prescriptions than men for the same problems, especially obesity, and are up to four times more likely than men to be prescribed activity limitations by their physicians, even with the same complaints, personal preferences, and illness behavior.[17] Studies evaluating how providers care for patients presenting with chronic knee pain showed that physicians are less apt to recommend "aggressive" treatment options (e.g., surgical versus medical management) for women patients compared with male patients, despite evidence that women suffer from more intense pain than men.[18] Providers should be mindful of their own biases and how these may influence the therapeutic relationship.

WOMEN'S REPRODUCTIVE HEALTH CARE

> Ellen asks her provider about starting Depo Provera injections on two successive visits. Her physician, concerned about Ellen's poor glycemic control and elevated blood pressure, defers the discussion until after she can review information about optimal contraceptive methods in the chronically ill. When Ellen is seen 2 months later, she is pregnant.

For many women, reproductive health-care issues predominate during their premenopausal adult lives. The need for safe and effective contraception, abortion, and prenatal care cuts across economic lines; yet, access to these services is strongly influenced by social position, geography, and political will. Limits on vulnerable women's access span all areas of reproductive health care, including screening and treatment of common causes of infertility. Moreover, women's sexual function, apart from their contraceptive needs, is rarely addressed and is poorly understood by most providers.[19]

UNINTENDED PREGNANCY

Unintended pregnancy has significant implications for women's health, the health of their families, and society. In the United States, around 6.6 million pregnancies occur each year, of which approximately half are unintended. In 2008, approximately 40% of these unintended pregnancies (excluding miscarriage) ended in abortion (1.1 million).[20] Just over half of all publically funded births were the result of unintended pregnancy (1.1 million), and government expenditures on these births totaled $12.5 billion.[21]

Of the women who become pregnant unintentionally, approximately 46% report using contraception during the month they conceived; either the method failed or it was used incorrectly.[22] In general, unintended pregnancies disproportionately affect women of low income, and African-American and Hispanic women.[23] Women who experience unintended pregnancy are at increased risk of experiencing negative maternal and infant health outcomes compared with women who have successfully planned for pregnancy.[24,25]

Health disparities in unintended pregnancy can be understood by looking at three factors: patient preference and behaviors, health-care system factors, and provider-related factors.[23] Health-care providers may contribute to disparities in a number of ways. For example, women with low literacy levels, or lack of English language proficiency, may find it difficult to understand much of the contraceptive information provided to them, and subsequently struggle to select a contraceptive method that best fits their needs.

BARRIERS TO EFFECTIVE CONTRACEPTION

Health-care providers play an important role in determining women's success with contraception. Helping each woman to choose a contraceptive method that satisfies her unique individual needs and goals requires the clinician to engage in detailed patient education and to facilitate shared decision making. This includes understanding her experience with contraception and helping her identify priorities for a method, which can include efficacy, convenience, and side effects. Providing accurate information and reducing barriers to accessing contraception is essential to contraceptive success.

From the provider perspective, barriers to contraceptive success include limited time available in the clinical

setting to address contraception in detail; not having a clear understanding of contraindications, efficacy, and side effects of individual methods; and inability to provide methods that require procedural skill, such as intrauterine or subdermal device placement. These issues are particularly relevant for women who live in areas without dedicated family planning clinic access. Women living in medically underserved communities, and who lack financial means to obtain health care elsewhere, may be forced to seek contraception in a setting that (1) limits their choices (particularly of long-acting methods), (2) is unable to provide contraceptives on site, or (3) uniformly links contraceptive access to preventive care (e.g., requiring a Pap smear before prescribing contraception).

Contraceptive knowledge in general varies by race and ethnicity, and influences contraceptive choice. Decreased contraceptive knowledge is associated with decreased utilization of the most effective contraceptive methods. Compared with white and black women, Hispanic women report the lowest levels of knowledge surrounding contraception. Women of color also are more likely to report increased skepticism surrounding various forms of contraception methods, and are more likely to hold beliefs that third parties are trying to limit their fertility.[26] Thus, providers that appear to be biased toward one or a few particular methods (e.g., Intrauterine devices (IUDs) and implants) may be viewed with mistrust by patients. When performing contraceptive counseling, providers should be cognizant of these disparities in contraceptive knowledge and cultural attitudes surrounding contraception.

Systemic issues related to contraceptive failure include lack of funding for contraceptive care. For example, funding for Title X, a federal program that provides free or low-cost family planning care to many low-income women in the United States, has decreased by 58% since 1980, limiting contraception access for uninsured women. Even poor women with private health insurance may lack coverage, as only 24 states currently have laws that mandate contraception coverage for private insurance companies that provide prescription drugs and devices. The landscape of contraceptive access in the United States is changing, however (with the possible exception of religious employers claiming exemption). The Affordable Care Act, signed into law by President Obama in March 23, 2010, now requires all health plans to cover basic preventive services, including all FDA-approved contraceptive methods, with zero cost sharing or copay on the part of the beneficiary. Evidence has demonstrated that when all methods are offered free of cost, a large proportion of women choose highly effective contraceptives. In the Choice Project, a study of 10,000 women offered no-cost contraception, 67% chose intrauterine devices or implants.[27]

Still, even women with insurance coverage often face additional barriers to accessing contraception such as limitations on the number of pill packs they may obtain at a time. This requires women to make regular and frequent visits to the pharmacy in order to use their contraception correctly. To this regard, it is worth noting that not having a "new pill pack" has been identified as a top reason women miss a pill.[28] Women with insurance may also not be able to access contraception due to lack of confidentiality from the primary insurance holder, who, as their partner or parent, may be unsupportive of contraception. In all of these cases, limitations on women's ability to access contraception can result in unintended pregnancy.

Barriers to contraception extend beyond funding and can directly influence the services available, even to women who have coverage. The merger of many religious and secular health care institutions, especially in communities where there are no other hospitals, has contributed to decreased access to contraception. In many such hospitals, providers are not allowed to perform sterilization procedures, place subdermal or intrauterine devices, or prescribe emergency contraception to patients in need. In addition, faith-based clinics offering care to homeless and poor women often do not provide contraceptive care. In some cases, providers refuse to prescribe, or pharmacists refuse to dispense contraceptives prescribed to women, citing their own personal code of ethics.[29]

Finally, even after choosing a method, many women do not fill prescriptions because of ambivalence, misunderstanding, lack of empowerment, or inability to pay for the method. Additional barriers to effective contraception include cultural and religious prohibitions against contraception, partner dislike of contraception, and mistrust based on medicine's historical treatment of women related to their reproductive lives (Box 34-1).

ACCESS TO ABORTION

Each year, more than a million women undergo an abortion in the United States. Most women have limited access to abortion services, especially rural women, teens, and poor women. Ensuring the availability of safe, legal abortion care is important, as numerous studies have found that where abortion is safe and legal, maternal mortality and morbidity are lowest.[30]

In the United States, abortion access has decreased over the last 15 years for a variety of reasons, including a shortage of practitioners who provide abortions, limited public funding for abortion services, and dramatically increased political restrictions. Between 2011 and 2013, 205 new political restrictions to abortion have been enacted.[31] As of 2011, only 11% of US counties had an abortion provider.[32] A minority of ob-gyn and family practice residency programs provide routine abortion training, although this number is increasing in response to ob-gyn residency

Box 34-1. Pitfalls Limiting Contraceptive Success

Provider-related factors

- Not having a clear understanding of contraindications, efficacy, and side effects of individual methods
- Concerns about medical conditions delaying contraception initiation
- Misinformation about criteria for initiating contraception (e.g., parity and IUDs)
- Inability to provide methods that require procedural skill
- Limited time available in the clinical setting to address contraception in detail
- Lack of effective communications and counseling skills
- Conscience/moral objection leading to failure to prescribe certain methods

Health-care system factors

- Protocols in place that impede a patient's access, such as waiting periods to ensure she is not pregnant or does not have sexually transmitted infection
- Misconceptions regarding clinical practice
- Unnecessary procedures prior to selecting a contraception method, such as Pap smear and other methods of cervical cancer testing
- Unnecessary follow-up scheduling that requires frequent visits
- Decreased Title X funding
- Insurance/Employer does not provide contraception coverage
- Lack of confidentiality from the primary insurance holder
- Religious prohibitions against contraception
- Limited range of contraception options available
- Restrictions on the amount of contraception that can be dispensed at one time
- Drug/drug interactions that modify efficacy of contraception

Patient factors

- Low contraception knowledge regarding various options
- Uncertainty about contraceptive method of action and efficacy
- How to optimize efficacy
- Undesirable side-effect profile of contraception
- Lack of financial resources to pay for/obtain desired contraception
- Failure to fill prescription
- Ambivalence toward contraception, and unintended pregnancy
- Partner dislike of contraception
- Mistrust based on medicine's historical treatment of women related to their reproductive lives

accreditation requirements, and initiatives by individual residency programs in both disciplines.[33,34]

Legislative restrictions on abortion access include numerous barriers on the state level, all of which disproportionately affect poor women and young women. Examples of legislation decreasing the delivery of abortion services include mandated waiting periods before a woman can obtain an abortion, parental consent requirements for minors seeking abortion, barring of Medicaid funding for abortion, and placing onerous requirements on physicians who provide abortions, as well as on centers where abortions are performed. These requirements have resulted in widespread abortion clinic closures, and a decreased number of abortion providers. For women, these requirements have resulted in increased challenges accessing abortion, and frequently contribute to significant delays in women's ability to obtain an abortion. In fact, studies have found that restrictive abortion[35] legislation has resulted in women, particularly minors, seeking abortions at later gestations, especially in the second trimester.[36] In addition, lack of community support and violent acts directed at abortion clinics, providers, and patients all limit women's access to safe abortion services.

INFERTILITY

In the United States, 7.4 million women have utilized infertility services.[37] Infertility, defined as the inability to conceive after 1 year of unprotected intercourse, is common.[38] Estimates suggest that as many as one in eight couples are infertile.[39] Infertility impacts couples of all racial and economic classes; however, black women and women of lower SES experience disproportionate rates of infertility.[40] While there are many causes of infertility, lack of access to appropriate health screenings and treatment may partially explain these disparities. For example, untreated sexually transmitted infections (particularly chlamydia and gonorrhea) may lead to inflammation of the fallopian tubes (salpingitis), and subsequent tubal occlusion. Black women and women of lower SES are more likely to contract these infections, and less likely to undergo screening and receive treatment for these infections.[41]

Paradoxically, while black and lower SES women experience disproportionate rates of infertility, they are the groups least likely to have access to assisted reproductive technologies. There are many reproductive technologies utilized to assist in achieving pregnancy including ovulation induction medications, intrauterine insemination, and in vitro fertilization (IVF). However, the process of IVF is cumbersome and cost prohibitive to most couples, averaging $12,400 per cycle.[42] The average success rate, defined as achieving a term pregnancy, is at best 40% per IVF cycle.[43] Thus, many couples must undergo multiple IVF cycles to achieve a pregnancy. These services are not

accessible to many couples required to pay out of pocket. Insurance coverage of IVF varies widely by state and insurance policy. At present, only 15 states have laws requiring insurance coverage for infertility treatment; however, this coverage does not universally include IVF.[44]

CHRONIC ILLNESS IN WOMEN

In the United States and other developed countries, the middle years of a woman's life are generally a time of good health, with low mortality rates. For hundreds of millions of women in other parts of the world, infectious diseases, particularly HIV and TB, continue to take a high toll. Noncommunicable chronic diseases—cardiovascular diseases, diabetes, cancers, and chronic respiratory diseases—account for 80% of deaths among adult women in high-income countries and 25% of the deaths in women between the ages of 20 and 60 years in low-income countries, where common illnesses such as diabetes mellitus and cardiovascular disease are on the rise in women.[13]

Although women in the United States are living longer with their chronic illnesses, living longer does not always mean living better. Chronic physical and mental illnesses contribute to significant disability in both younger and older women. The burden of decreased access to preventive services and treatment experienced by those of lower SES compounds the suffering from these common illnesses. Moreover, when chronic illness in women is not controlled, it can have devastating effects on children and other family members.

STRATEGIES FOR IMPROVING WOMEN'S HEALTH

ECONOMIC AND SOCIAL JUSTICE FOR WOMEN

The World Health Organization's Constitution states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."[45] Access to affordable, high-quality health care is essential to achieving this goal. However, in order to achieve improved health status for women, their position in society must be improved across racial and economic lines. The disparities that exist between women and men, and between women of color and white women, are rooted in social inequalities that must be addressed in tandem with efforts to improve health status (Box 34-2). For example, low wages and poverty are significant predictors of poor health outcomes. Because gender and race significantly impact one's earning potential, advocacy surrounding equal pay for equal work is not only fair but also has the potential to increase the health status of women and minorities.[46] Furthermore, it has been shown that interventions such as microfinance combined with gender equality training and initiatives that address gender inequality and communication and relationship skills hold promise for improving women's health and lives.

Box 34-2. World Health Organization Gender Glossary

- Gender is used to describe those characteristics of women and men, which are socially constructed, whereas sex refers to those that are biologically determined. People are born female or male but learn to be girls and boys who grow into women and men. This learned behavior makes up gender identity and determines gender roles.
- Gender equality is the absence of discrimination based on a person's sex in opportunities, the allocation of resources and benefits, or access to services.
- Gender equity refers to fairness and justice in the distribution of benefits and responsibilities between women and men. The concept recognizes that women and men have different needs and power and that these differences should be identified and addressed in a manner that rectifies the imbalance between the sexes.

Adapted from WHO gender policy: Integrating gender perspectives in the work of WHO. World Health Organization. Accessed September 4, 2014. Available at http://www.who.int/gender/documents/policy/en/.

IMPORTANCE OF WOMEN IN FAMILY AND COMMUNITY HEALTH

Women's central role in reproduction, and the management of their families, positions them to have a considerable impact on their own health, and the health of their children, partners, elders, and the community. In the United States, women make the vast majority (80%) of health decisions for their families.[47] Women more often than men are responsible for choosing their children's physicians, taking their children to appointments, and making decisions regarding their family's health insurance. However, because women juggle so many roles and responsibilities, they often find it difficult to prioritize their own health-care needs.

Strong and healthy women are integral to building strong and healthy families. Therefore, one strategy to encourage women to prioritize tending to their own health needs may be to frame caring for one's own health as ensuring the health of the family as well. Women's (and men's) ability to have healthy and happy families, while earning income sufficient to support their needs, is part and parcel of ensuring community health, and should be supported and defined by public policies.

WOMEN PROVIDERS

Women patients prefer female physicians in a variety of settings, from the emergency room to obstetric and gynecologic care. This may be due to increased comfort working with individuals of the same gender, or it may be related to differences in the practice patterns of male and female physicians. For example, women physicians on average spend more time with patients, converse more, and appear to listen more closely, resulting in greater reported patient satisfaction. Women physicians are also more likely to perform appropriate preventive health screening and counseling on their patients.[40,48] Nurses and mid-level providers, nurse practitioners, physician's assistants, and midwives expand the number and influence of women in health care. However, as is the case across industries, women do not equally occupy leadership positions in medicine. This means that women's issues—both women patients' and women physicians' issues—are not equally represented or considered at the top health administration levels. Though women currently comprise over 50% of medical school matriculants, and account for roughly 54% of instructors at medical institutions, in 2011, female physicians led only 12% of the departments at these institutions.[49] Promoting women within the leadership ranks of medicine is an important next step in assuring the care of women is optimized across medical specialties.

COORDINATED SERVICES

> After reviewing her pregnancy options with her physician, Ellen decides to continue her pregnancy. She is referred to a high-risk obstetrics clinic that accepts her insurance. There, Ellen sees her obstetrician along with a nutritionist, social worker, and diabetes nurse. Although it is challenging to get to her appointments, she now receives the support she needs to manage her diabetes during pregnancy.

Given the many competing priorities in women's lives, and the resulting lack of time for self-care, offering multiple complementary services at one site is optimal. Simultaneous access to mental health services, substance abuse treatment, nutrition counseling, and social support can make it possible for a woman to realistically address her health-care needs. Ensuring timely access to specialists is another important component of coordinated medical care. Simple changes such as offering evening and weekend hours, walk-in visits, and being located close to public transportation are successful measures that enhance low-income women's ability to access health services.[50] Addressing women's care-giving responsibilities by welcoming children in the physician's office or even providing brief supervision for children and elders during visits would facilitate many women's use of care.

COMMUNITY OUTREACH AND ADVOCACY

In addition to offering coordinated care in easily accessible locations, bringing health care and information to women where they live and work is an essential part of improving outcomes. For example, church-based breast cancer screening programs have been shown to improve mammography rates in hard-to-reach women.[51] Day-care-based educational programming targeted toward parents of children with asthma has been shown to reduce child (and parent) absences from school (and work).[52] Providing community-based care to women and their families is most effective when the needs and priorities of the community drive the effort.

GROUP VISITS

Social support is critical for many women as they navigate and fulfill their health-care needs. Social support in the setting of group-based care has been found to positively affect health outcomes (see Chapter 16). For example, group prenatal care has been shown to improve outcomes for minority and low-income women, resulting in higher birth weights, particularly for infants born preterm. Group-based care has a positive effect by providing a needed social support network to women who, because of the isolation imposed by poverty or immigration, might otherwise lack such a network.[53]

FAMILY PLANNING

Family planning exists on a spectrum. Across a woman's reproductive lifespan, her priorities regarding family planning may fluctuate. At times, the goal may be to prevent pregnancy, while at other times, the priority may be to achieve a healthy pregnancy. Just as women experience challenges preventing pregnancy due to difficulty accessing contraception and abortion services, poor and underserved women in particular may experience challenges achieving pregnancy due to lack of access to both preventive and infertility care.

Preconception Counseling

With nearly half of pregnancies being unintended, preconception care must be integrated into the routine health care of reproductive aged women (Box 34-3). This is particularly important for underserved women who bear a higher burden of chronic illness, poor birth outcomes, and limited access to care. In addition to anticipatory guidance, including discussion of contraception, common issues in preconception care include achieving a healthy body weight, screening and treatment for infectious diseases and substance use disorders, immunization updating, control of chronic illnesses, and medication review. Women who are chronically ill will have better pregnancy

Box 34-3. Preconception Guidelines

- Ask all reproductive age women about intention to become pregnant.
- Contraceptive counseling based on patient's plans and desires.
- Assess weight: counsel both over- and underweight women influence on birth outcomes.
- Counsel those with chronic illnesses about the importance of preconception control, especially in smoking, diabetes, seizures, thyroid, and substance use.
- Screen for chronic illness or exposures in high-risk groups.
- Counsel all diabetics that tight control prior to conception improves outcomes.
- Review medications, inform patients of any teratogenic effects and for those desiring pregnancy soon change to safer medications if necessary.
- Screen patients for sexually transmitted diseases, and other infectious diseases in higher risk groups—i.e., immigrants for hepatitis B, tuberculosis, etc.
- Review immunization records and update vaccines as needed.
- Advise folic acid supplementation (400 μg daily) prior to conception.
- Advise contraception during rapid weight loss phase of bariatric surgery.

outcomes if these illnesses are controlled prior to conception. Control of diabetes mellitus, asthma, hypertension, seizures, substance use, and thyroid disorders are crucial to healthy pregnancies and children.

Wanting a healthy pregnancy and child may be a potent incentive for improving health. Smoking and other substance use cessation, blood sugar control, and weight loss all improve birth outcomes. Bariatric surgery may improve fertility in many women with previous obesity induced insulin resistance. Women undergoing bariatric surgery should be provided contraception during the rapid weight-loss phase and counseled to avoid pregnancy immediately post-op. Before conception, women should be screened for nutritional deficiencies that are a common complication of bariatric surgery.

Addressing Women's Contraceptive Health Needs

To best address women's contraceptive needs, providers should have easy access to the most up-to-date contraception information. There are several excellent reference guides and Web sites to assist providers and patients in understanding the variety of methods, prescribing information, contraindications, efficacy, and side-effects (see "Resources").[54]

When caring for women with medical problems, there are a number of reliable resources available to help providers select contraceptive methods that are safe and effective for their patients. Two excellent resources include the World Health Organization Medical Eligibility Criteria (MEC) and the updated U.S. MEC published by the CDC, which cover an expanded set of medical illnesses and circumstances. These guidelines make clear recommendations about which contraceptive methods are safe in women with dozens of medical diseases. An additional CDC guideline, the Selected Practice Recommendations, details aspects of contraceptive practice to make contraception provision easier.

It is appropriate for providers to routinely address contraception during the patient encounter. Contraceptive success depends on patient satisfaction with their contraceptive method. Therefore, it is important to carefully elicit patients' contraceptive preferences before directing patients toward a particular method. Often providers assume that efficacy and convenience are consistent with their patients' top priorities, and direct their contraceptive counseling toward IUDs and implantable devices. However, many women prioritize other aspects of contraception such as side effects (e.g., regular bleeding profiles) and control of the method (e.g., such as being able to discontinue without a clinician's assistance).

When performing contraceptive counseling, providers should work with their patients to identify their contraceptive preferences, and offer recommendations and education about methods that fulfill their goals. This type of contraceptive counseling is an example of shared decision making, and exemplifies patient-centered care. Early studies evaluating shared decision making in the family planning setting have found women find this method of counseling highly acceptable.[55] In addition, preliminary studies have found that women who participate in shared decision making when selecting their contraception method report higher degrees of satisfaction with their method compared with women who did participate in this model of counseling with their clinician. To increase long-term contraceptive success, providers may consider offering triage access for refills, and phone consultation about side effects.

In the past, it was common practice for physicians to require women to obtain Pap smears or pelvic examinations before the initiation of hormonal birth control methods. However, this practice is not evidence based, is medically unnecessary, and is now actively discouraged by reproductive health experts including the American College of Obstetricians & Gynecologists. The practice of "holding contraception hostage" to routine preventive health care is bad medicine as it may result in fewer women getting needed contraception, particularly teens or others who may have personal fears or taboos around the pelvic examination. With the exception of a blood pressure measurement prior to initiating combined hormonal contraception, no physical examination is necessary before initiating a combined hormonal method.[56]

Finally, emergency contraception, taken within 5 days of unprotected intercourse, decreases the risk of unintended pregnancy by approximately 74% depending on method and time since intercourse (with lower efficacy associated with increased time).[57] Emergency contraception consists of levonorgestrel pills (Plan B) totaling 1.5 mg, or ulipristal acetate (Ella) in a single 30 mg dose. Ulipristal acetate is slightly more effective than levonorgestrel, and is the only effective regimen in women with a BMI greater than 26 (ulipristal acetate is effective up to a BMI of 35).[35] While emergency contraception is available over the counter in the United States for women aged 17 years and older, providers should still offer women advanced prescriptions for emergency contraception, as this act has been shown to increase women's utilization of emergency contraception, without decreasing their likelihood of utilizing their main contraceptive method.[58]

Ensuring Abortion Access

Many providers caring for women will encounter patients facing unwanted pregnancy. In order to assure all patients have access to the health-care services they need, providers should decide whether they feel comfortable offering objective pregnancy options counseling and referrals for the medical services a patient desires, including abortion services, information about adoption, and prenatal care. There are a number of resources that can assist a provider that does not feel comfortable providing unbiased pregnancy options counseling or referring for abortion. Local Planned Parenthood Federation Affiliates are able to offer counseling and referral services in almost all communities. In addition, numerous objective pregnancy options counseling hotlines exist including services administered by the National Abortion Federation (1-800-772-9100), backline (1-888-493-0092), and Faith Aloud (1-888-717-5010).

Patients must not always leave their established physician to access abortion services. Individual practitioners, including ob-gyns, family physicians, internists, and (in a few states) advanced-practice clinicians, may offer medical and/or early surgical abortion within their offices contingent upon institutional policies and attitudes.[31,59] Even if physicians do not directly participate in the provision of abortion services, physicians who support women's right to safe abortion play an important role in assuring services remain accessible in their communities. Publically supporting your local abortion provider and abortion clinic is just one step physicians of any specialty can take to increase the acceptability and integration of abortion into mainstream medicine.

Advocacy to Eliminate Barriers to Effective Family Planning

Women's health is currently at the forefront of much ongoing political debate. Legislative restrictions on women's access to contraception, abortion, and family planning services have grown exponentially as of late. Between 2011 and 2013, 205 restrictions on women's access to abortion services were enacted across the United States—more restrictions than seen in the entire previous decade.[61] On June 30, 2014, the US Supreme Court ruled that employers could omit contraceptive coverage from health-care plans provided to employees based on religious grounds (Burwell v. Hobby Lobby, 2014), despite the Affordable Care Act including contraception as an "essential benefit," and mandating its coverage at no direct cost to women.[62,63]

Women deserve access to smart and compassionate medical care. Restrictive abortion and contraceptive policies have the potential to harm women's health.[64,65] Advocacy on many fronts will be necessary to address and rescind current policies that restrict access to abortion and endanger women's health. Advocating for removal of punitive abortion restrictions and continued protection of abortion's legal status is best accomplished by professional, legislative, and judicial efforts. Continued advocacy by women's health supporters will also be necessary to ensure adequate public funding is appropriated for Title X family planning clinics and contraceptive coverage in general.

- Poor women and women of color suffer a higher burden of disease but receive a lower quality of health care.
- Because of the competing demands of work and family, women often put their own health and well-being last.
- Women's health-care needs are compartmentalized, and different providers understand each other's areas poorly.
- Effective contraception is denied because of political barriers, lack of funding, or inextricable linkage to routine health-care screening.
- Women's sexual function is rarely addressed.
- Cultural preferences, language, and literacy are frequently not incorporated when providing contraceptive information.

CONCLUSION

The path to improving the health of women in vulnerable communities, and indeed all women, is rooted in efforts to eliminate social inequalities. Being mindful of the many personal and systemic barriers to good care and directly addressing them through personal and political advocacy, integration of services, improved access, and examining one's own perceptions about women patients are all part of providing the best possible care.

Evidence-Based Strategies to Optimize Contraception Use

When	What to Do
Prior to the appointment	• Plan to routinely discuss contraception with reproductive-aged women. • Have available a written or Web-based reference of contraceptive contraindications, efficacy, and side-effects, to help women choose a method.
History/ Counseling	• Practice shared decision making throughout your contraceptive counseling. • Ask your patient what qualities she values most in a contraceptive method (e.g., efficacy, bleeding predictability, control over method termination, etc.). • Provide information about contraceptive methods that meet your patient's preferences including education about advantages, disadvantages, and side-effects of those methods. • Encourage your patient to ask questions and respond with evidence-based information. • Clarify misconceptions or concerns your patient has regarding contraceptive methods of interest. • Facilitate the selection of a mutually agreeable contraceptive method, and develop a plan to optimize its usage. • Review what to do if she forgets to use the method when scheduled. • Give her literacy-appropriate handouts about her method of contraception. • Reassure your patient she can change contraceptive methods at any time. • Give her a prescription for EC and information about how to use it.
Physical examination	• Do not require a screening Pap smear before prescribing a method. The only required examinations are a blood pressure measurement before prescribing combined hormonal methods, and a pelvic exam before IUD insertion.
Assessment and plan	• Use your references to confirm contraindications.
After the appointment	• Have staff readily available for questions and refills. • Do not require examinations before giving refills.

DISCUSSION QUESTIONS

1. You are involved in the planning stages of a women's clinic in a low-income community. What structural elements would you include to make your services more accessible to your target patient population?
2. Ms. Chen is a 37-year-old woman with hepatitis C who comes to you seeking contraception. How would you counsel her about her options? What resources would you consult to determine the safety of contraceptive methods in a woman with a medical illness?
3. Consider the approach to providing contraception in your current practice setting. Generate a list of three specific changes you could make to improve your patients' access and compliance with contraception.

RESOURCES

Association of Reproductive Health Professionals (ARHP). ARHP is an organization that provides continuing medical education for health practitioners in reproductive health. http://www.arhp.org.

Medical Eligibility Criteria for Contraceptive Use. An online resource produced by the World Health Organization that gives clear, evidence-based guidelines about the use of contraception in women with medical illness. http://www.who.int.

United States Medical Eligibility Criteria (US MEC) for Contraceptive Use. An online resource produced by the Center for Disease Control and Prevention, similar to that produced by the WHO, providing women and clinicians with guidance regarding the safety of different contraceptive methods in women with various medical conditions and available as an app from most app stores. http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5904a1.htm?s_cid=rr5904a1_e.

U.S. Selective Practice Recommendations (US SPR) for Contraceptive Use. An online companion document to the US MEC produced by the CDC, which provides clinical guidance regarding the initiation and use of specific contraceptive methods in women with complex medical conditions. http://www.cdc.gov/reproductivehealth/UnintendedPregnancy/usspr.htm.

National Women's Health Indicators Data Base is a national catalog of health indicators that highlights issues of racial, economic, and gender disparities. http://www.healthstatus2000.com/owh/select_variables.aspx.

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A patient- and clinician-centered interactive Web site about contraception with great evidence base is found at http://bedsider.org/.

Resources about abortion—both US and global perspective—containing disparity data, graphs, slide presentations, etc., is found at the Guttmacher Institute Web site: http://www.guttmacher.org/.

Preconception Care Guidelines including tools for patients and provider can be found at http://www.cdc.gov/preconception/reproductiveplan.html.

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Chapter 35

Intimate Partner Violence

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Objectives

- Define intimate partner violence (IPV), childhood exposure to IPV, and the epidemiology of IPV globally and in the United States.
- Describe the health effects of IPV.
- Describe risk factors for perpetration and victimization of IPV.
- Review recommended screening, assessment, and intervention practices to address IPV in the health-care setting.

Jasmine grew up in an underserved urban neighborhood in the United States. Her father was an alcoholic who frequently assaulted her mother. When Jasmine was 14, her mother committed suicide, leaving Jasmine homeless. She has had a series of abusive boyfriends who have beaten and sexually assaulted her. She began using heroin a few years ago.

Amina grew up in a small village in Tanzania. Her father routinely beat her mother and insisted that Ahadi get married at age 16 to an older man with many other wives who offered to pay for Ahadi. Ahadi knows that when one of his other wives requested that he use a condom, he beat her so badly that she almost died. Ahadi is now pregnant with her third child.

INTRODUCTION

Intimate partner violence (IPV) is a global epidemic and human rights issue. It has marked harmful effects on the safety, health, and overall well-being of those victimized, their families, and communities. The term intimate partner violence describes physical violence, sexual violence, threats of physical or sexual violence, and psychological abuse by a current or former intimate partner. IPV may occur throughout the lifespan, from adolescence to old age. While IPV is related to child abuse as children who are exposed to parental or guardian IPV are often also the victims of direct maltreatment (Table 35-1) and may become both victims and perpetrators in adulthood, discussion of child abuse and elder abuse are beyond the scope of this chapter.

For many victims, the health-care setting is the only safe point of contact outside of the abusive relationship and presents an ideal opportunity to identify and address IPV. Health-care providers who effectively screen for and address IPV can be the difference between life and death for victims of IPV and their families. This chapter describes IPV and provides an overview of how to address IPV in the health-care settings serving vulnerable populations.

EPIDEMIOLOGY AND HEALTH EFFECTS

The overall burden of IPV on girls and women is of epidemic proportions. An estimated 30% of women worldwide have experienced physical and/or sexual violence perpetrated by their intimate partner.[1] In the United States, more than one in three women (35.6%) have experienced physical violence, rape, and/or stalking by an intimate partner in their

Table 35-1. Definitions of intimate partner violence (IPV), Child Exposure to IPV, and Child Abuse

Term	Definition
IPV	"[a] pattern of assaultive and coercive behaviors that may include inflicted physical injury, psychological abuse, sexual assault, progressive social isolation, stalking, deprivation, intimidation and threats. These behaviors are perpetrated by someone who is, was, or wishes to be involved in an intimate or dating relationship with an adult or adolescent, and are aimed at establishing control by one partner over the other"[a]
Child exposure to IPV	"…a wide range of experiences for children whose caregivers are being abused physically, sexually, or emotionally by an intimate partner. This term includes the child who observes a parent (or guardian) being harmed, threatened, or murdered, who overhears these behaviors… or who is exposed to the short- or long-term physical or emotional aftermath of a caregiver's abuse without hearing or seeing a specific aggressive act…"[a]
Child maltreatment (abuse)	"An act or failure to act by a parent, caretaker, or other person as defined under State law which results in physical abuse, neglect, medical neglect, sexual abuse, emotional abuse, or an act or failure to act which presents an imminent risk of serious harm to a child"[b]

[a]From National Consensus Guidelines on Identifying and Responding to Domestic Violence Victimization in Health Care Settings. 2002, The Family Violence Prevention Fund: San Francisco, CA.1-72 (National Health Resource Center on Domestic Violence 2002).
[b]From What is Child Abuse and Neglect? 2004, The Department of Health and Human Services: Washington, DC (National Clearinghouse on Child Abuse and Neglect Information 2004).

lifetimes, and 18.3% of all women have been raped in their lifetimes. Ninety percent of all rapes are committed by an intimate partner or an acquaintance.[2] Globally, more than 38% of all female homicides (and 6.3% of male homicides) are committed by an intimate partner.[3] In the United States in 2008, around 45% of female and 5% of male homicides were committed by an intimate partner.[4]

In medical settings, the prevalence of IPV is higher, likely due to the physical and mental health sequelae of IPV that prompt IPV victims to seek care. A study of adult patients seeking primary care at an urban public hospital revealed that 15% of women reported abuse within the last year, and 51% reported abuse in their lifetime.[5] In the United States, IPV costs a staggering $8.3 billion annually due to $5.8 billion in medical costs for injuries and health sequelae and $2.5 billion in lost productivity.[6]

Most victims of IPV are women and women are far more likely than men to be injured when victimized by an intimate partner. Nevertheless, there is increasing recognition of IPV with male victims.[2,7] Lesbian and gay people have rates of IPV victimization equal to or higher than heterosexual people,[8] but rates for people who identify as bisexual are significantly higher.[2] The prevalence of IPV among transgender people is not well studied but likely to be higher than in gender-conforming people.[9]

In adolescents and adults, IPV victimization results in poor mental and physical health, and sometimes life-long disability. IPV is also associated with a higher prevalence of chronic diseases including arthritis, asthma, stroke, heart attack, heart disease, hyperlipidemia, chronic pain, and high-risk behaviors such as tobacco use, heavy alcohol use, and high-risk sexual behaviors.[10] In addition, IPV victimization correlates with mental health problems including posttraumatic stress disorder, anxiety, depression, suicidality, eating disorders, and substance use.[11] Globally, suicide rates are significantly elevated in women victims of IPV.[12]

As demonstrated by the histories of Jasmine and Amina, victims of IPV often have little control over their own sexual and reproductive health. Their partners are often non-monogamous, refuse to use condoms, sabotage birth control methods, and coerce them into unwanted pregnancies or abortions.[13,14] Such reproductive coercion often results in an increased prevalence of unwanted pregnancy, abortion, HIV, other sexually transmitted infections (STIs), and gynecological problems.[11] In parts of the world with high HIV prevalence, IPV has emerged as an important risk factor for HIV transmission.[15] In addition, IPV is associated with poor birth outcomes such as fetal low birth weight, preterm births, and miscarriages.[16] Furthermore, young women forced into early and abusive marriages are at extremely high risk of adverse maternal outcomes such as preeclampsia. Male IPV victims who have sex with men are also at increased risk for forced unprotected anal intercourse, as well as higher rates of depression, HIV, and substance abuse.[17]

It is estimated that almost 9 million children are exposed to parental or guardian IPV each year in the United States alone.[18] Children may witness physical, sexual, and emotional violence; be caught in the "crossfire" of violent acts; or suffer direct child abuse. More than 50% of children who are exposed to IPV are also directly abused.[19] Children exposed to IPV have multiple mental health, physical health, and behavioral problems including posttraumatic stress disorder, depression, anxiety, chronic somatic complaints, learning problems, increased aggression, fearfulness, and developmental problems.[20,21] Adverse childhood experiences, such as being abused or witnessing parental violence, are increasingly being recognized as key determinants of health that have an impact

on biological processes and brain development. Adverse childhood experiences often result in risky adult behaviors (e.g., smoking cigarettes, using drugs, having a higher number of sexual partners) and adulthood chronic diseases[22] (see Chapter 36.)

There is an emerging body of literature examining perpetration of IPV. More than 40% of men attending urban clinics in a US city reported perpetrating physical and sexual IPV in the past year.[23] Male perpetrators of IPV often have increased rates of childhood exposure to IPV and histories of child abuse.[24] Recognizing and addressing this cycle of violence is essential to prevent children who are exposed to violence from growing into adults who perpetrate IPV. Moreover, men who perpetrate IPV are at risk for other poor health outcomes: they have high-risk sexual behaviors and a higher risk of being HIV positive, as well as have high rates of injury, psychiatric disease, substance use, irritable bowel syndrome, and insomnia.[24]

FRAMEWORK FOR UNDERSTANDING INTIMATE PARTNER VIOLENCE

> Jasmine's current partner, Carl, grew up in a family in which his father was an alcoholic who severely beat his mother, Carl, and Carl's siblings. Carl never completed high school. He has been abusive to each of his girlfriends. Carl has been incarcerated twice for "domestic violence" and has never held a job for more than a few months.

An "ecological model" has been developed to conceptualize individual, relationship, community, and macrosocial factors that support the development and persistence of IPV (Figure 35-1).[25] The Centers for Disease Control and Prevention (CDC) maintains lists of these evidence-based factors that increase or decrease the likelihood of IPV such as employment and educational status and substance use (Table 35-2). An understanding of these multilevel factors can help identify various opportunities for prevention.

Many IPV victims and perpetrators lack these factors, and many men and women with these factors do not necessarily experience IPV. Violent relationships are "passed on" from one generation to the next as witnessing IPV or being abused by parents are associated with victimization and perpetration of IPV as an adult.[26]

Table 35-2. Risk Factors for Intimate Partner Violence

Individual risk factors
- Low self-esteem
- Low income
- Low academic achievement
- Young age
- Aggressive or delinquent behavior as a youth
- Heavy alcohol and drug use
- Depression
- Anger and hostility
- Antisocial personality traits
- Borderline personality traits
- Prior history of being physically abusive
- Having few friends and being isolated from other people
- Unemployment
- Emotional dependence and insecurity
- Belief in strict gender roles (e.g., male dominance and aggression in relationships)
- Desire for power and control in relationships
- Perpetrating psychological aggression
- Being a victim of physical or psychological abuse (consistently one of the strongest predictors of perpetration)
- History of experiencing poor parenting as a child
- History of experiencing physical discipline as a child

Relationship factors
- Marital conflict—fights, tension, and other struggles
- Marital instability—divorces or separations
- Dominance and control of the relationship by one partner over the other
- Economic stress
- Unhealthy family relationships and interactions

Community factors
- Poverty and associated factors (e.g., overcrowding)
- Low social capital—lack of institutions, relationships, and norms that shape a community's social interactions
- Weak community sanctions against IPV (e.g., unwillingness of neighbors to intervene in situations where they witness violence)

Societal factors
- Traditional gender norms (e.g., women should stay at home, not enter workforce, and be submissive; men support the family and make the decision)

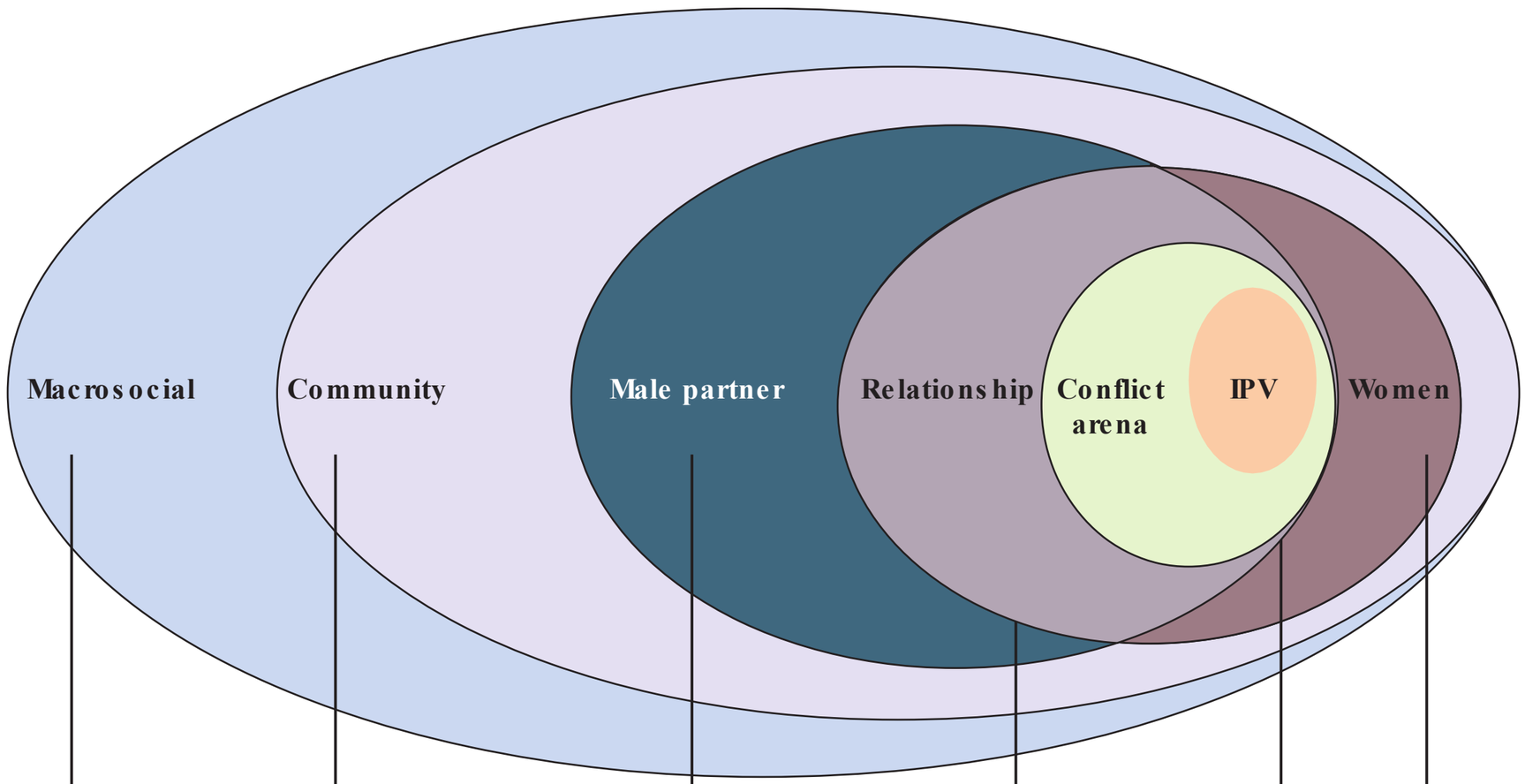
Source: From Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Division of Violence Prevention. Available at http://www.cdc.gov/ViolencePrevention/intimatepartnerviolence/riskprotectivefactors.html. Accessed July 8, 2015.

ADDRESSING INTIMATE PARTNER VIOLENCE IN THE HEALTH-CARE SETTING

SCREENING FOR INTIMATE PARTNER VIOLENCE

> Trevor is a 25-year-old man who presents for primary care complaining of daily headaches. Trevor's male partner is very concerned about Trevor and accompanies him into the exam room. The provider allows Trevor's partner to join the visit, takes a detailed history of Trevor's headaches, and schedules a brain MRI. When Trevor returns, he sees a covering provider who separates Trevor from his partner and inquires about IPV. She learns that Trevor's headaches began after his partner started abusing him physically and sexually.

Multiple professional medical associations in the United States now recommend routine universal screening for IPV victimization based upon its high prevalence, myriad adverse health effects, and infrequent identification when not done routinely.[27-29] Routine screening for IPV is recommended by Joint Commission



Gender order

Lack of economic rights & entitlements for women

Discriminatory family law

Ease of divorce for women

Composite measures of gender inequality

Cultural factors

Collectivist versus individual cultural orientation

Emphasis on women's purity & family honour

Economic factors

Level of development

Women's access to formal wage employment

Norms

Acceptance of wife beating

Male right to discipline/ control female behaviour

Tolerance of harsh physical punishment of children

Stigma for divorced or single women

Norms linking male honour to female purity

Family privacy

Lack of sanctions

Lack of legal or moral sanction for violence

Others do not intervene

Neighbourhood

Community violence

High unemployment

Low social capital

Poverty

Violence in childhood

Harsh physical punishment

Witnessing parental violence

Other childhood traumas

Psychological dysfunction

Antisocial behavior

Adult attachment issues

Attitudes

Accepting of violence as a means to resolve conflict

Acceptance of partner violence

Gender hierarchical or transitional attitudes

Alcohol abuse

Gender role conflict

Delinquent peers

Sociodemographic

Young

Low educational level

Interaction

Non-equalitarian decision making

Poor communication

High relationship conflict

Conflict arena

Situational triggers

Sex/infidelity

Money/distribution of family resources

Children or in-laws

Division of labor

Male drinking

Patriarchal triggers

Female challenge to male authority

Failure to meet gender role expectations

Assertions of female autonomy

Childhood violence

Child sexual abuse

Other childhood traumas

Witnessing mother being beaten

Attitudes

Tolerance of wife beating

Socio-demographic

Young age (for current violence)

High educational attainment (protective)

Low social support

Factors that operate differently in different settings:

Women's employment

Participation in credit schemes or other development programs

Asset ownership

Figure 35-1. Revised conceptual framework for partner violence. Factors are color coded to communicate the strength of the evidence base linking that particular factor to the experience of partner violence. Factors colored blue have the strongest evidence base, green have medium evidence, and pink have the weakest or fewest number of studies supporting their role in partner violence. Factors in the far right-hand column (relating to the woman) have been consistently shown across studies and settings to increase a women's risk of victimization. The remaining columns represent factors that have been shown to increase the likelihood of men's perpetrating partner violence. Many related to the male partner show up repeatedly in multivariate analysis of cross-sectional surveys from low- and middle-income countries. Longitudinal cohort and intervention studies reinforce this evidence in many instances. Significantly, however, many of these more sophisticated studies come exclusively from high-income settings. (From Heise L. What works to prevent partner violence? An evidence overview. STRIVE, London School of Hygiene and Tropical Medicine: London, 2011:7.)

on Accreditation of Healthcare Organizations for all hospitalized women,[30] all women of childbearing age by the United States Preventive Services Taskforce,[31] and is covered as an essential health service by all insurance companies under the Affordable Care Act.[32] Additionally, the vast majority of patients state that they would like their health-care providers to ask them about IPV and that merely disclosing IPV privately to a trusted provider who responds compassionately is highly therapeutic.[33] Routine screening and identification of IPV in health-care settings is beneficial and offers a crucial opportunity to support victims and break repetitive cycles of violence.

Unfortunately, most recommendations address IPV victimization in women only, leaving out gay male patients like Trevor, transgender male patients, and gay and heterosexual male patients, including boys, who present with indicators of abuse. Yet, there are guidelines about how to screen for and address IPV victimization in women and men including LGBTQ patients.[9,28,34] We recommend adopting a universal screening approach for all girls and all women and those boys and men in high-risk populations.

In addition, people who perpetrate IPV are regularly seen in health-care settings but are rarely screened for IPV perpetration. Ultimately, in order to prevent IPV victimization, addressing perpetration is necessary. There is expert guidance on addressing IPV perpetration with men,[34] but scant research in this area.[24,35,36]

SCREENING FOR INTIMATE PARTNER VIOLENCE: BEST PRACTICES

> Amalia is a Spanish-speaking, undocumented woman whose husband David first started criticizing her during her pregnancy. Since then, he has hit Amalia on numerous occasions. David has threatened to have Amalia deported if she reveals the abuse. When Amalia takes her daughter, Elena, to the pediatrician, he sees Amalia's exhausted appearance, and says, "You look so tired and upset. I'm worried about you. Has David ever hit you or hurt you in any way?" Amalia says, "I'm afraid that he will hurt me if he finds out I'm talking to you."

Reporting requirements for IPV and child abuse vary widely; therefore, clinicians need to learn about them for their specific locality, state, or country. The goal of screening is not to force disclosure of IPV but, rather, to express concern for a patient's safety, respect for the patient's autonomy, and offer help as needed. Through the development of compassionate, trusting relationships, the health-care team and community advocates can help reduce the patient's isolation and increase the patient's sense of empowerment. With proper training, various members of the health-care team can inquire about IPV. To ensure patient safety, professionally trained medical interpreters (rather than family members or friends) should be used to screen for and respond to IPV. The patient should be alone and in a private location when asked about IPV.

Detailed guidelines and validated tools for screening exist.[21,28] (See https://secure3.convio.net/fvpf/site/Ecommerce/236886779?VIEW_PRODUCT=true&product_id=-1861&store_id=1241; https://secure3.convio.net/fvpf/site/Ecommerce/1501428096?VIEW_PRODUCT=true&product_id=1811&store_id=1241.)[37,38] Ideally, screening for IPV occurs within the context of a patient-centered conversation that is made relevant to the patient's health. In general, direct questions (including questions about emotional abuse and reproductive coercion) increase identification of IPV, whereas vague questions about safety rarely elicit disclosures of IPV (Box 35-1). Introductory phrases can facilitate clinician and patient comfort with screening: "Because violence in relationships is so common, I ask all my patients about it. Has your partner ever hit, hurt or threatened you?"

Box 35-1. Tools to Screen and Assist with Intimate Partner Violence

Mnemonics

HITS[a] tool: How often does your partner

- **H**urt you physically
- **I**nsult you
- **T**alk down to you
- **T**hreaten you with harm
- **S**cream or curse at you?

Direct questions

- "Has your partner ever hit you or hurt you?"
- "Has your partner ever threatened you or frightened you?"
- "Has your partner ever forced you to have sex or do something sexual you didn't want to do?"

Questions about emotional abuse

- "How does your partner treat you?"
- "Does your partner yell at you or frequently criticize you?"

Additional questions about sexual/reproductive coercion

- Has your partner tried to force you to become pregnant or have an abortion?
- Does your partner interfere with your birth control?
- Does your partner (if male) refuse to wear a condom?

[a]Sherin KM, Sinacore JM, Li XQ, et al. HITS: A short domestic violence screening tool for use in a family practice setting. Fam Med 1998;30:508-512.

Recent studies have examined a variety of screening approaches beyond provider interview, including a "video doctor," computer-assisted screening, and written patient questionnaires.[39-41] A majority of patients prefer non–face-to-face disclosure (e.g., through a computer interface or written survey), but many patients do not. Given overall low rates of screening in health-care settings, we encourage the use of multiple modalities to improve screening practices and honor individual patient preferences.

Validated, practical clinical tools for screening for IPV perpetration have not been developed and tested. Research suggests that men who perpetrate IPV under-report current IPV perpetration in face-to-face encounters, but may be willing to discuss past perpetration.[35,36] Both men and women who perpetrated violence against someone close to them were willing to utilize a computer-assisted screening and intervention tool.[42] While screening for IPV perpetration, it is important to maintain the confidentiality of the IPV victim and screen for perpetration in a way that does not suggest that the victim disclosed IPV to the provider.

BARRIERS TO ADDRESSING INTIMATE PARTNER VIOLENCE

PATIENT BARRIERS

The Victim

The main challenge to addressing IPV is that the person perpetrating IPV uses physical, sexual, and emotional abuse; social isolation; economic deprivation and control; abuse of children, pets, and property to maintain control; and erode a victim's sense of worth. Victims report that their partners directly restrict them from obtaining medical care and threaten violence if they reveal IPV.[43,44] They describe multiple barriers to disclosure including fear of retaliation; low self-esteem and shame; sense of family responsibilities; and fear of loss of custody, socioeconomic barriers, the health-care provider being too busy or treating the patient negatively, and of consequences of mandatory reporting or police involvement.[33]

These barriers are often magnified in vulnerable populations and IPV may compound other health disparities. Disclosing IPV requires that a patient place extraordinary trust and faith in the health-care system. This trust may not exist for a patient from communities that have not been traditionally well served in the health-care setting. People from minority and underserved communities may have poor access to high-quality culturally accountable care for the sequelae of IPV. Women with disabilities are a particularly vulnerable group. Language barriers between victims and providers may decrease the effectiveness of IPV screening and treatment.[45] In addition, victims with undocumented legal status or visas that are dependent on their spouses, like Amalia, are often reluctant to disclose IPV for fear of deportation. Many undocumented immigrant victims are unaware that they can apply for emergency protective orders and that there are legal ways of seeking citizenship independent of one's spouse.[46] Collaborating with legal and community-based organizations that can provide culturally and language-concordant services often reduces the stigma and fear that these vulnerable victims face.

The Perpetrator

Evidence about barriers to disclosing perpetration is lacking. People who are perpetrating IPV often minimize and deny their abusive behavior, feel that they themselves are the victims, blame the victim for the abuse, and lack empathy for those they hurt. If perpetrators are aware of the illegal nature of their acts, they may fear disclosure to a health-care provider.

HEALTH-CARE PROVIDER BARRIERS

There is mounting evidence that clinicians do not follow recommended guidelines for addressing IPV in the health-care setting.[47] Clinicians have described multiple barriers to addressing IPV, including concern for offending the patient, their discomfort with cultural issues, having a personal history of exposure to abuse, and frustration with screening and interventions that are seen as futile. Providers also express practical concerns: they may not have time to screen for and respond to IPV; they fear the repercussions of mandatory reporting on patient safety; and they feel they lack adequate education and training about IPV.[47]

HEALTH SYSTEM BARRIERS

Despite new guidelines and mandates to implement routine, universal IPV screening in the United States and recommendations to implement targeted IPV screening worldwide, there remains a lack of system-wide commitment to their implementation. Institutions that do not incorporate multiple system changes find it difficult to increase routine IPV screening and IPV identification rates. Many practice settings lack access to trained staff and the resources required to institute an ideal, comprehensive program. Lack of societal resources and laws governing the protection of women, girls, and populations vulnerable to IPV in many countries further hinder the health-care response to IPV. Finally, there is insufficient commitment to the development of programs to address IPV perpetration.

- Failing to inquire directly about IPV
- Blaming the victim for IPV
- Advising the victim to "leave" rather than addressing safety
- Failing to give adequate attention to the needs of children affected by IPV
- Failing to respond to IPV experienced by health-care providers
- Failing to develop a coordinated response to IPV
- Lacking a health-care response to the perpetration of IPV
- Failing to implement comprehensive IPV programs in health-care organizations
- Lacking culturally appropriate models for addressing IPV

ASSESSMENT OF INTIMATE PARTNER VIOLENCE

> Elena's pediatrician supports Amalia, "No one deserves to be treated this way." He explains the extent of confidentiality of the visit. He asks her about David's whereabouts, her immediate safety, and that of Elena. He assesses her emotional state for suicidality. He asks her what she wants to do.

IMMEDIATE

Most patients who disclose IPV will disclose past IPV. Providers should still assess how this experience affected a patient's life, whether the patient has ongoing contact and/or threats from her or his partner, whether children were involved in the relationship, and how children are coping with the aftermath of the relationship.

In the case of current IPV, immediate assessment in the medical setting should include inquiry about the perpetrator (e.g., current whereabouts, access to weapons) to establish whether the patient and staff are in any potential danger. The clinician can then inquire about the imminent risk to the victim and children, history of abuse of the children, the emotional state of the victim, and the degree of readiness or desire for change on the part of the victim. In assessing for imminent risk, it is important to inquire about threats with weapons, past use of weapons, whether the victim thinks she or he is in danger of being killed and other evidence-based lethality factors.[4]

OVER TIME

The breadth of an assessment done in a primary care setting depends on the preference of the patient, the acuity and severity of the IPV, the expertise of the clinician and health-care team, scheduling constraints, and the availability of community services. In some health-care settings, the entire assessment and response to IPV may occur within the health-care setting. In most cases, the health-care team and community IPV advocacy and other services share both assessment and response to IPV. Over time, it is important for the multidisciplinary team to identify the history and pattern of abuse; the physical, psychological, economic, and social effects of the abuse; and the history of injuries or hospitalizations.

Assessment can be a strong empowerment tool. Emphasizing the patient's strengths and coping mechanisms during each step of the assessment and highlighting the connection between the patient's health problems and the abuse may help the patient decide to make changes that increase safety. It can be especially motivating to help a patient understand the effects of abuse on children.

IPV perpetrators may be screened for a personal history of childhood abuse and adverse childhood experiences in order to foster understanding of the possible childhood roots of later perpetration of violence. Assessment for the effects of IPV perpetration on any children and for accompanying direct child abuse should be done. Providers must attempt to assess for lethality potential and should understand the laws governing their duty to warn intended victims of imminent danger.[34]

INTERVENTION IN INTIMATE PARTNER VIOLENCE

> Elena's pediatrician repeats supportive statements: "The abuse is not your fault. No one deserves to be treated this way." He suggests that the stress caused by David's abusive behavior affects Amalia's ability to breastfeed her daughter. He emphasizes that both Amalia and Elena deserve to be safe. Amalia agrees to attend an appointment in a trauma therapy program that treats victimized parents and their children together.
>
> He helps Amalia call a hotline, asks the hotline staff to help with safety planning, gives her the phone number of a local shelter for Latina women, and asks her whether she would like to file a police report. She is too frightened to file a police report now but learns how to call the police and what to say to them. The hotline counselor explains that Amalia can apply for citizenship independent of David.

The importance of providing emotional support and pointing out the patient's strengths is a critical component of intervention, and cannot be emphasized enough (Box 35-2). Because a patient who is experiencing trauma may have trouble absorbing what is happening during the health-care visit, repetition of messages of support

Box 35-2. Intervention: Guiding Principles

- Regard safety of adult victims and their children as a priority.
- Respect the integrity and authority of each victim of IPV over her/his life choices.
- Hold person perpetrating IPV responsible for the abuse and for stopping it.
- Advocate on behalf of victims of IPV and their children.
- Intervention strategies should include the following:
  - Telephone numbers for local and national 24-hour crisis lines
  - Referral to culturally appropriate community services
  - An opportunity to develop a personal, specific safety plan in conjunction with the health-care team, community advocates, or both[49] (see model plan at http://www.leapsf.org/html/safety_plan.shtml).
  - An opportunity to file a police report; if the patient wishes, a member of the health-care team or a community advocate can stay with the patient during the interview
  - Referral to legal services; the federal "Violence Against Women Act" (VAWA) provides funding for family violence programs. It also mandates that victims of violent crimes may apply for citizenship with specific visas and that married persons who are victimized by a legal resident or US citizen spouse may proceed with their immigration process independently; however, the burden of proof is high and requires specialized legal assistance.

From Warshaw C, Ganley A. Improving the Health Care Response to Domestic Violence: A Resource Manual for Health Care Providers. San Francisco: Family Violence Prevention Fund, 1998. Available at https://secure3.convio.net/fvpf/site/Ecommerce/1046506243?VIEW_PRODUCT=true&product_id=1805&store_id=1241. Accessed September 22, 2014.

VAWA provisions described at http://www.uscis.gov/humanitarian/battered-spouse-children-parents. Accessed September 30, 2014.

Find safety planning documents at http://www.leapsf.org/html/safety_plan.shtml.

is critical. Widening the circle of support for the victim by connecting her or him with supportive members of a multidisciplinary team is also vital: Each person will connect with the victim in an important, different way. In the event of imminently life-threatening emergencies, police need to be summoned immediately. Leaving an abusive relationship can be extremely dangerous, and is often when women are at highest risk of being a victim of homicide.[48] Although it is difficult for clinicians to accept, improving safety may or may not involve separation from a partner in the near future. Suspected or confirmed child abuse and neglect must be reported to Child Protective Services (CPS). In some US states, merely witnessing IPV is considered reportable. It is essential that the health-care team advocate for and attend to the safety of both the victimized parent and the children.

There is growing but still limited data on the efficacy of various interventions to assist victims of IPV. There is evidence that intensive advocacy interventions can reduce physical abuse in women leaving shelters and may improve quality of life. Although results are inconsistent, there are 13 IPV intervention studies done in health-care clinics that demonstrate some benefit including the reduction of IPV, women's increased use of safety behaviors and IPV community resources, and health benefits.[31,48,49] A brief, nondisclosure-based counseling intervention done in a family planning clinics markedly reduced reproductive coercion (but not IPV).[50] Studies have not found any harms associated with intervening. Clinicians find that addressing the physical and mental health sequelae of IPV is essential to further empowering victims of IPV. Referral to mental health providers with experience in treating patients affected by IPV and other forms of trauma is essential. Child–parent therapy to help heal the parent and child individually as well as the parent–child relationship is recommended.

FOLLOW-UP WITH PERPETRATORS

> During treatment in the parent–child program, Amalia leaves David. David begins to drink more heavily. He is brought to the emergency department (ED) for a seizure. An ED provider elicits a history of IPV and refers him to a program for perpetrators.

There is no evidence to suggest that purely health-care setting–based interventions will diminish IPV perpetration. There is general agreement that perpetrators should at least be provided with messages that their behaviors are harmful, they are responsible for stopping these harmful behaviors, their children are at heightened risk of learning to participate in violent relationships, and that they are capable of change. Because transformative change is challenging and, most often, occurs slowly, referrals to IPV perpetration treatment programs for adults and dating violence prevention programs for adolescents is recommended. Unfortunately, current evidence suggests that current batterer's intervention programs in the United States are not highly effective. These programs reach very few perpetrators of IPV and the dropout rates are very high even when court mandated.[51,52] Yet, perpetrators do

experience "turning points" that may lead to change.[53] Because many perpetrators of IPV continue to be involved in their children's lives, some experts have begun to explore the challenging field of "fatherhood and domestic violence."[54] A report summarizing the global research on preventing IPV in low- and mid-income countries highlights programs such as the gender-norm changing "Sisters for Life" curriculum which, when combined with a microfinance program, reduced IPV by 51% over 2 years.[25] Because it is so difficult to stop violence once it starts, advocates and leaders are focusing on childhood and adolescent dating violence prevention and healthy relationship promotion efforts.

DOCUMENTATION OF INTIMATE PARTNER VIOLENCE

> Elena's provider documents "IPV" in Elena's electronic health record (EHR). Because the parent who is perpetrating violence may request pediatric chart and because the EHR does not allow for the protection of sensitive information, the clinic policy is to review all record requests and redact data as necessary for safety before releasing information.

Guidelines have been developed that discuss the proper documentation of IPV in medical records.[28] It is important to document as many specifics as possible, use the victim's own words in quotes, and describe injuries with detailed descriptions, diagrams, and photographs. Unfortunately, EHRs are not required to be designed to protect sensitive data or to allow for varying degrees of privacy. Health-care institutions must try to protect patient privacy and safety by adapting the EHR (if possible) and adopting appropriate policies and procedures.

INSTITUTIONAL SOLUTIONS

A "systems change" approach seems the most promising for institutionalizing IPV programs. An ideal system-wide response would address both victimization and perpetration and the effects of IPV on children. It would require collaboration with community services, the police, and the justice system; be culturally responsive and accountable; fully coordinate family services; and include mental health, substance use, social services, and advocacy.

FAMILY VIOLENCE PREVENTION PROGRAM AT KAISER PERMANENTE

Kaiser Permanente developed and disseminated nationally a "KP Systems Model" to ensure an effective response to IPV that has resulted in an eightfold increase in IPV identification and increased provider referrals of patients to IPV treatment, patient and staff awareness, and patient satisfaction.[55]

The KP Systems Model (link to http://share.kaiserpermanente.org/article/about-our-program/) is based upon a supportive environment that provides both patients and providers with easy access to information and encouragement for IPV disclosure. Frequent, focused, brief training is given to providers. Tools embedded in the EHR support providers to offer routine IPV screening, make expedited referrals, and follow best practices and, also, allow for dissemination of key components of the Systems Model. On-site behavioral health clinicians assess the mental health needs of IPV victims and begin a safety-planning process. Robust linkages to community IPV organizations ensure access to both crisis and ongoing IPV advocacy services. At each medical center, a multidisciplinary team, led by a physician champion, provides leadership and oversight of the Systems Model. Finally, the IPV identification and referral rates are monitored through a continuous quality improvement process to stimulate IPV program improvements.

FUTURES WITHOUT VIOLENCE

Futures without Violence, an international nonprofit working to end violence, has developed quality improvement tools that describe the ideal components of a comprehensive health-care setting IPV prevention and treatment programs (see http://www.healthcaresaboutipv.org/getting-started/quality-improvement-goals-and-performances-measures/).

VICARIOUS TRAUMATIZATION AND STAFF INTIMATE PARTNER VIOLENCE

Working with patients affected by IPV can take an emotional toll on already overworked and stressed health-care providers. Medical providers and health-care staff are not immune to IPV and almost invariably, during the process of implementing IPV programs, staff privately or publicly self-identify as being affected by IPV.

CONCLUSION

IPV is a common and devastating problem that has long-term health consequences for all members in a family. Although the challenges are many, clinicians, given their access to the intimate lives of their patients, are uniquely situated to address IPV and ameliorate the suffering not only of their patients but of generations to come as well.

- **Address IPV with each patient.**
  —Ask all women about IPV (and, once you are experienced in asking, ask men about IPV also).
  —Provide supportive messages to victims of IPV.
  —Provide safety planning to victims of IPV on-site or through community agencies.
  —Provide culturally appropriate resources and referrals to victims and perpetrators of IPV.
  —Document IPV and its effects with detail (through direct quotes, diagrams, and photos) and monitor for EHR-related safety and privacy problems.
- **Address the effects of IPV on children.**
  —Ask how children are exposed to IPV.
  —Advocate for the victimized parent's safety when Child Protective Services or other authorities are involved.
  —Advise treatment of children in a program that specializes in trauma treatment for children.
- **Use institutional supports to encourage providers to address IPV.**
  —Establish a screening, treatment, and safety protocol.
  —Provide ongoing, interactive training for all staff.
  —Incorporate written or electronic chart prompts and tools.
  —Address patient–provider confidentiality issues.
  —Assess adherence to protocol through routine quality improvement studies.
- **Make resources available to all patients regardless of whether IPV is disclosed.**
  —Place posters prominently in health-care settings.
  —Place small safety cards in private places (bathrooms, examination rooms).
  —Directly advertise and educate all patients about culturally specific and appropriate IPV services.
  —Post crisis phone numbers and the national hotline 1-800-799-SAFE.
- **Establish a mechanism for supporting health-care staff.**
  —Support health-care staff directly affected by IPV.
  —Support all health-care staff exposed to patient trauma by routinely addressing vicarious traumatization.

Intimate Partner Violence (IPV) Screening and Treatment Guidelines for Medical Providers

Screening

1. Establish privacy (screen patient alone)
2. Use staff or trained medical interpreters if needed (not family or friends)
3. Ask direct questions:
   - Has your partner ever hit you, hurt you, or threatened you?
   - Does your partner make you feel afraid?
   - Has your partner ever forced you to have sex when you didn't want to?
4. Ask indirect questions:
   - How does your partner treat you?
5. Ask about past history of IPV:
   - Have you ever had a partner who hit you, hurt you, or threatened you?
   - Have you ever had a partner who treated you badly?
   - Have you ever had a partner who forced you to have sex or to do something sexual you didn't want to do?

Assessment

Assessment of current IPV
Assess immediately
1. Safety in clinic
   - Is perpetrator with patient?
2. Current safety
   - Threats of homicide
   - Weapons involved
   - History of strangulation or stalking
3. Suicidality and homicidality
4. Safety of children

Assess over time
1. Pattern of abuse
2. History of effects of abuse
   - Injuries/hospitalization
   - Physical and psychological health effects
   - Economic, social, or other effects
3. Support and coping strategies
4. Readiness for change

Assessment of past IPV
1. Current safety ("Are you (and your children) safe from this person now?")
2. History of effects of abuse
   - Injuries/hospitalization
   - Physical and psychological health effects
   - Economic, social, or other effects

Intervention

1. Give repeated messages of support
2. Offer crisis phone numbers
3. Assist in preparing a safety plan (or connect patient with a person who can)
4. Offer advocacy and counseling
5. Offer police and legal assistance
6. Arrange for follow-up visits and a safe way to contact patient
7. Expand the patient's support to multiple members of a multidisciplinary team if patient agrees (provider, community and clinic based advocates, social worker, nurse, counselor, etc.)

Documentation

1. History
   - Write legibly
   - Use patient's own words in quotes
   - Document as much info as patient will provide regarding specific events (who, what, where, when)
2. Physical findings
   - Describe injuries in detail
   - Draw diagrams of injuries
   - If patient consents, take photographs of injuries
   - Take serial photographs of injuries over time
3. Physical evidence
   - If patient consents, preserve physical evidence in paper bag
   - Describe physical evidence in detail

Reporting

1. If patient is injured, file a mandatory health-care report to police (in California)
2. If you suspect children are being neglected or harmed, file a CPS report. (Advocate on behalf of adult victim/survivor's safety with CPS)
3. If patient is ≥65 or a dependent adult, file an Adult Protective Services (APS) report

Source: From Kimberg.[34] Available at www.leapsf.org.

DISCUSSION QUESTIONS

1. Discuss how speaking limited English (or one's culture, race, ethnicity, sexual orientation) might affect one's experience with IPV and one's interaction with the health-care system.
2. Discuss ways you have introduced (or could introduce) the topic of IPV with patients and then role play, asking about IPV and being supportive to a patient affected by IPV. How would you change your approach in a pediatric setting?
3. Imagine you have a patient who was severely abused as a child and presents to the health-care setting in repeated abusive relationships. How would you approach this patient? How might you sustain your morale while working with this patient over time?

RESOURCES

Websites:

http://futureswithoutviolence.org

http://www.healthcaresaboutipv.org/

http://www.leapsf.org

http://www.cdc.gov/ViolencePrevention/index.html

http://raisingvoices.org/

http://www.breakthecycle.org/

http://www.loveisrespect.org/

Videos:

http://strive.lshtm.ac.uk/resources/sasa-video-prevent-violence-against-women-now-subtitled

See http://www.healthcaresaboutipv.org/ for multiple video scenarios on how to discuss IPV with adolescent and adult patients

http://www.leapsf.org/html/training.shtml

Books:

Mitchell C, Anglin D. (eds). Intimate Partner Violence: A Health-Based Perspective. New York: Oxford University Press, 2009.

Saakvitne KW, Pearlman LA. Transforming the Pain: A Workbook on Vicarious Traumatization. New York: WW Norton & Company, 1996.

Lieberman A, Van Horn P. Don't Hit My Mommy: A Manual for Child-Parent Psychotherapy with Young Witnesses of Family Violence. Washington, DC: Zero to Three Press, 2004.

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Chapter 36

Trauma and Trauma-Informed Care

Leigh Kimberg, MD

Objectives

- Define trauma.
- Describe the risk and protective factors for trauma.
- Review the effects of trauma on health.
- Review how childhood trauma results in adulthood disease and poor outcomes.
- Describe ways of addressing trauma in health care.

INTRODUCTION

Marta is a 23-year-old woman who brings her healthy 3-year-old child in for a check-up with her new family practice provider. She presented to her prior provider's office with severe headaches many times and has had an extensive workup. Today, she appears depressed and overwhelmed and says she cannot concentrate due to the headaches. When her new provider asks compassionately why Marta thinks she has headaches, Marta wonders if it could be that her father used to slam her head against the table if she did not know the answers to questions. Upon further questioning, Marta's provider learns that Marta's mother died when she was a baby. She was the youngest of six children in a poor family in Mexico. Her father was particularly abusive to her. When she was 16 she was taken to an older man's house and told that she was now married to him. She fled across the Mexico–US border. She does not want to talk about the journey across the border. Marta reveals to her new provider that she is worried that she does not know how to be a good mother.

Trauma is a leading cause of morbidity and mortality worldwide. Traumatic experiences refer to everything from being in a car accident to witnessing terrible events, being abused, or living through a natural disaster or a war. Traumatic events are more disruptive and likely to overwhelm a person's ability to adapt than the normal stresses and vicissitudes of life. Trauma's risks also multiply: being exposed to one traumatic event increases both individual and community risks for future traumatic events. The impacts of trauma are dependent on individual and community vulnerabilities, resources, and protective factors. Trauma, especially in childhood, causes health disparities. It is a root cause of adult disease and high-risk behaviors. Trauma also disproportionately affects the most vulnerable people and populations. Trauma prevention and treatment are evolving and improving. Addressing trauma in the health-care setting holds the potential to more effectively improve health, decrease suffering, and promote the achievement of health equity.

DEFINITION OF TRAUMA AND TYPES OF TRAUMATIC EVENTS

Defining trauma is challenging. The term "trauma" is often used interchangeably and inconsistently to refer to events and to the outcomes of the events. Defining an event as traumatic depends on the totality of circumstances. Each person may respond to a similar event differently based upon the circumstances surrounding the

event and the interplay between genetic, epigenetic, biological, psychological, environmental, family, community, societal, historical, and other factors. Thus, most experts now understand that trauma is a process that involves the interaction between an event or series of events and the individual and community's vulnerability, protective and resiliency factors. If an event or series of events overwhelms the person or community's capacity to adapt in a positive manner and instead lead them to suffer adverse consequences, then the event is considered traumatic.

In discussing trauma the terms individual trauma and complex trauma are often used. The Substance Abuse and Mental Health Services Administration (SAMHSA) defines individual trauma (http://www.samhsa.gov/nctic/about):

Individual trauma: "Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being."

Complex trauma or complex psychological trauma, on the other hand, is defined as "resulting from exposure to severe stressors that (1) are repetitive or prolonged, (2) involve harm or abandonment by caregivers or other ostensibly responsible adults, and (3) occur at developmentally vulnerable times in the victims' life, such as early childhood: . . ."[1] but, can also occur later in life.

Trauma may happen to individuals and to entire communities or cultural groups. A traumatic event may be a one-time occurrence. Much more often, it is a series of traumatic events or prolonged exposure to traumatic circumstances. Events or experiences that are traumatic for human beings include catastrophic environmental events (both natural and human influenced); various types of accidents; large-scale violence (e.g., war, genocide, torture, human trafficking, terrorism, and forced migration); "structural violence" that involves systematic oppression or discrimination (e.g., racism, homophobia, and transphobia); interpersonal violence, family violence, childhood or adult sexual assault, abuse and neglect (see Chapter 35); and life events that reduce trust or a sense of safety and security such as the death of loved ones, divorce of one's parents, major illness, or other life upheavals. This chapter focuses mainly on traumatic events that involve some type of individual interpersonal violence, abuse, or neglect. Nevertheless, to understand, treat, and prevent interpersonal violence, consideration of the broader societal context is necessary.

PREVALENCE OF TRAUMA

Exposure to some form of trauma is exceedingly common. Traumatic deaths represent a small fraction of the total burden of trauma. Globally, more than 5 million people die annually of injuries. These traumatic deaths represent 9% of all deaths worldwide and exceed the deaths from HIV/AIDS, malaria, and tuberculosis combined.[2] In 2011 in the United States, injuries, including all causes of unintentional and violence-related injuries combined, accounted for 51.3% of all deaths among persons 1–44 years of age (more deaths than noncommunicable diseases and infectious diseases combined).[3] In 2012, homicide was the third leading cause of death for 15- to 34-year-olds and the fourth leading cause of death for 1- to 14-year-olds in the United States.[4] Almost 90% of a national random sample of US residents (who had Internet access) has experienced exposure to a very serious traumatic event (meeting DSM-5 criterion A).[5] Exposure to physical or sexual assault over the lifespan for adults in this sample was 53.1% (see Chapter 35).

In one of the largest, most comprehensive studies of the effects of childhood trauma on adulthood disease, the "Adverse Childhood Experiences" (or "ACE Study"), the high prevalence of trauma occurring during childhood has been highlighted.[6] In this study, 17,337 adults enrolled in care in Kaiser Permanente's Health Appraisal Clinic in San Diego completed questionnaires about 10 categories of traumatic events (called "adverse childhood events" or "ACE's"), including childhood emotional, sexual, and physical abuse; neglect; and familial dysfunction (i.e., witnessing of parental domestic violence, separation, or divorce; or mental illness, substance use or incarceration in a household member). Each category of adverse events is scored as either present or absent and given one point. In this predominantly white, middle-class population, 63.9% of the participants had experienced at least one ACE category and 12.5% had experienced four or more ACE categories. Having one ACE markedly increases the risk of having more than one ACE. Twenty-five percent of the women and 16% of the men reported childhood sexual abuse, a traumatic event rarely identified in the health-care setting.

While adverse childhood experiences are quite common in all communities and the overall ACE score does not vary widely by race/ethnicity, they are more common in communities plagued with adversity such as poverty, low educational attainment, and low employment.[7,8] The ACE study also does not measure adversity that exists outside of the family and household, such as community violence or structural violence. The burden of overall trauma in urban underserved communities is thought to approach that of conflict-ridden developing countries.[9] The Institute for Safe Families in Philadelphia has developed an "Urban ACE score" that includes measures of witnessed community violence, adverse neighborhood experiences, bullying, and discrimination.[10] The World Health Organization has developed and is validating an "ACE International Questionnaire" that includes additional questions related to forced marriage, peer violence, exposure to

community violence, and war and collective violence (link: http://www.who.int/violence_injury_prevention/violence/activities/adverse_childhood_experiences/en/)

The prevalence of trauma in certain disease states is startling high. Increasingly, these diseases are seen as symptoms of the larger epidemic of trauma. For example, among women living with HIV, the rate of intimate partner violence (IPV) is 55%, which is even higher than the rates among national samples of women (36%). The rates of childhood sexual abuse and physical abuse are 39% and 42%, respectively, more than twice the national rates of 16.2% and 22.9%. Lifetime sexual abuse among women living with HIV is 61%, more than five times the national rate (12%).[11]

RISK FACTORS FOR TRAUMA

David lives with his mother in a neighborhood plagued by community violence, drug dealing, and chronic neglect by city government. David's father was arrested for domestic violence against his mother when he was 5 years old. As a young child, an uncle who lived with his family sexually abused him. David never told anyone. He attends an overcrowded, under-resourced, and underperforming school where he is frequently bullied and does very poorly in school. His mother, who works multiple jobs, spends hours commuting to work. She is never able to be home to care for David until very late in the evening. At the age of 16, David drops out of school, joins a gang for protection, and is shot in the leg in gang-related violence.

INTERPERSONAL VIOLENCE

Abuse and violence have been characterized as occurring within the context of an ecological model that takes into account individual, family, community, societal, and macrosocial factors (see Figure 35-1).[12] In this model, all forms of interpersonal violence are interrelated and there are common risk and protective factors that create conditions in which violence takes root or is prevented.[13] Any characteristic that is associated with diminished real or perceived power and status in society may be a risk factor for increased exposure to many traumatic events and experiences (Box 36-1).

Childhood is a particularly vulnerable time for trauma exposure. The youngest children (ages 0–5) are at the highest risk for exposure to trauma and this trauma may be repetitive and chronic.[14] Growing up without the care of a safe, responsive, nurturing caregiver dramatically alters healthy childhood development and sets a child up for a lifetime of future adversity. Parents are at increased risk of abusing or neglecting their children if they do not understand children's development or needs; have low levels of education and/or poor parenting skills; are unable to be attentive due to substance addiction or severe mental health problems; or have a history of being abused themselves during childhood.[14] Exposure to IPV markedly increases the risk of childhood maltreatment. In more than 50% of families with IPV, children are also abused.[15] Trauma begets more traumas in an intergenerational cycle. Mothers who were abused as children are more likely to abuse their children, and children who grew up observing IPV are more likely to be in a violent relationship as adults,[16] and thus, also have children who are exposed to IPV.[17]

Box 36-1. Risk Factors for Trauma

- Lack of safe, stable, nurturing relationships
- Young age
- Female sex for IPV/sexual violence
- Male sex for community violence
- Minority status (race, ethnicity, religion, sexual orientation, gender identity, other)
- Psychiatric illness
- Substance use
- Disability (physical and mental)
- Family history of violence
- Homelessness
- Poverty

SOCIAL ISOLATION

Social isolation of families and communities puts children at higher risk of being maltreated. In communities that have low "social capital" and are plagued by violence, poverty, housing instability, high density of alcohol sales, and poor social cohesion, the likelihood that children will be abused or neglected is increased (see http://www.cdc.gov/violenceprevention/childmaltreatment/riskprotectivefactors.html).

GENDER

Gender is highly correlated with the types of trauma that people experience. Violence against women and girls is a worldwide epidemic that includes childhood abuse and sexual exploitation and assault, IPV, rape by nonintimate partner perpetrators and as an instrument of war, "honor killings," and female genital mutilation. Men (and boys) perpetrate the vast majority of violence against women and girls; their risk of perpetrating violence against women and girls is increased if they have been abused as children themselves. Most often violence against women and girls is perpetrated by intimate partners, family members, and close contacts rather than strangers[12] (see Chapter 35). Natural disasters and warfare increase the

risk of sexual violence via nonintimate partners/strangers for women worldwide.[18]

Boys are also at risk of childhood abuse and childhood sexual exploitation.[19] Although among young children boys are at risk of violence within the family or by close contacts, adolescent and adult males are predominantly at risk of community and war violence that is perpetrated by other men. Worldwide, three quarters of all homicide victims are boys and men, especially those 15–29 years old. Community violence is a more common cause of homicide than war.[2] Yet, homicide represents a very small fraction of the devastating effects of abuse and violence. It is estimated that for every young person killed, there are many more young people who have injuries caused by violence.[2]

PHYSICAL AND MENTAL DISABILITIES

Physical and mental disabilities are both caused by trauma and markedly increase one's risk of violent victimization and trauma. The risk of child abuse, IPV, sexual violence, elder abuse, and community violence are all increased in people who are vulnerable due to disabilities. Discrimination on the basis of disabilities also leads to a multitude of disadvantages like poverty, homelessness, and lack of access to social and medical services that increase the likelihood of victimization (see Chapter 42).

MINORITY STATUS

Because various forms of discrimination and structural violence against minority-identified groups and individuals are tolerated and perpetuated in most communities worldwide, minority status in society is a risk factor for being exposed to trauma and multiplicative forms of trauma. For example, LGBTQ individuals are at increased risk of being bullied and are likely at increased risk of sexual assault.[20] People who identify as bisexual or lesbian or gay have a 58–66% increased risk of exposure to "ACEs" as compared with heterosexual people.[21] Transgender people experience extraordinarily high rates of violent victimization by strangers as well as intimate partners.[22]

People of minority race/ethnicity are targeted by discrimination resulting in trauma, often by the systems meant to serve them. When measured by household survey, race and ethnicity are not associated with any difference in the rate of child maltreatment.[23] Yet, African-American children are reported to child protective service authorities for child maltreatment at a 78% higher prevalence rate than that of white children.[24] Racial minorities, targeted by both historical and structural violence, are at dramatically increased risk of community violence. In the United States, between 2007 and 2009, the relative rate difference of homicide for non-Hispanic blacks was at least 650% higher than the rate reported for non-Hispanic whites. Hispanic and American-Indian/Alaskan native people in the United States also had higher homicide rates than non-Hispanic whites.[25]

The killing of young minority men in the United States by the police is a stark reminder of the traumatic effects of institutionalized racism. Official data are woefully inadequate in reporting exactly how much more often minorities are likely to be killed by police than whites in the United States and estimates vary widely. An analysis of federally collected data by Propublica shows that young black males in recent years were 21 times more likely to be killed by police than their white counterparts (http://www.propublica.org/article/deadly-force-in-black-and-white). The Centers for Disease Control and Prevention (CDC) data likewise reveal racial disparities in rates for both death and injury at the hands of police. According to the CDC, between 1968 and 2011, black people were between two to eight times more likely to die at the hands of law enforcement than whites. (National Violent Death Reporting System: http://wisqars.cdc.gov:8080/nvdrs/nvdrsDisplay.jsp and as reported in Mother Jones, 2014: http://www.motherjones.com/politics/2014/08/police-shootings-ferguson-race-data.) These data reveal a pattern of policing that produces racial disparity and inflicts extensive trauma in minority communities. Black and Latino men are also far more likely to be imprisoned than white men. Generations of minority children suffer the trauma that results from growing up with an incarcerated parent.[26]

POVERTY AND SOCIETAL NORMS

Poverty and societal norms regarding violence also influence the prevalence of violence and trauma in communities. Globally, high rates of income inequality and a society tolerant of violence are associated with high rates of youth violence.[27] Living in poverty and, more specifically, in a neighborhood with multiple forms of disadvantage increases one's risk of exposure to many traumatic experiences including abuse and neglect, hunger, inconsistent housing, family and community violence, parental substance use, severe maternal depression, discrimination, disease, loss of loved ones to premature mortality, and more.[13]

Trauma and homelessness are inextricably intertwined. Trauma may directly result in homelessness and homelessness increases the risk for subsequent trauma. Family violence and IPV are immediate causes of homelessness when children and adult victims must flee their homes. In a prospective, population-based longitudinal study, both childhood exposure to family adversity and experiences of violent victimization were found to be associated with increased risk of future homelessness.[28] In turn, homelessness in both adults and adolescents markedly increases the risk of future violent victimization.[29,30]

SUBSTANCE USE

Substance use is also highly correlated with the risk of violence and trauma. Worldwide, alcohol use has been found to increase risk for violent victimization and perpetration through multiple mechanisms including acute and chronic physical and cognitive impairment, increased aggression, the use of alcohol as an excuse to perpetrate violence, and more. Alcohol use increases the risk for violence and is increased by the experience of violence and abuse.[31]

PROTECTIVE FACTORS AGAINST TRAUMA

David's best childhood friend, Richard, lives with his mother and grandparents. His father is in jail. His mother works two jobs in order to make enough money to send Richard to a parochial school. When Richard was young, she treasured the 15 minutes she spent reading to Richard before bed. His grandparents picked him up from school and stressed the importance of doing his homework. Richard does well in school and his teachers help him apply to college and for financial aid. Richard dreams of becoming a lawyer to help people like his father, who he thinks was falsely accused of a crime he denies committing.

Protective factors that decrease the likelihood of trauma have not been studied as much as risk factors that increase the likelihood of trauma (Box 36-2). These protective factors also may be examined within the context of an ecological model that takes into account individual, family, community, societal, and macrosocial factors (see Figure 35-1).[12] Individual and family factors that protect against childhood maltreatment and violence include individual genetic expression, child IQ, nurturing parenting, parent–child relationship quality, and stable family relationships.[32,33] Additional protective factors include parental employment, housing stability, care by other supportive adults, and access to health and social services. Communities that are able to support parents and focus on preventing abuse and violence also protect children from maltreatment.[34]

The single most significant protective factor in preventing both childhood trauma and its adverse outcomes is the presence of a safe, stable, nurturing adult caregiver consistently present in a child's life.[35] In fact, in families in which the mother, who had experienced her own childhood maltreatment, grew up to have safe, stable, nurturing relationships with her intimate partner and her children, the risk of child maltreatment was equivalent to families in which the mother had not been maltreated as a child. Safe, stable, and nurturing relationships can effectively break the intergenerational transmission of abuse.[36]

Despite trauma and adversity, some children and adults are resilient and able to thrive. Resilience is the capability to surmount adversity. It refers to a "positive, adaptive response despite significant adversity." The close and responsive attention of a nurturing adult alters childhood development to promote resiliency not only due to the close relationship but also the skills-building and positive experiences that develop through this relationship.[35] Some researchers have proposed that resilience be reconsidered as a social-ecological construct in which the community rather than an individual is the source of resilience.[37]

Box 36-2. Factors Protective Against Trauma

- Supportive family relationships
- Secure communities
- Financial security
- Employment
- Stable housing
- Higher educational status
- IQ
- Community engagement
- Good health

CONDITIONS RELATED TO TRAUMA

David has chronic pain in his leg from his gunshot wound. He drinks three 48-ounce beers daily and smokes marijuana to "calm down." He contracts hepatitis C from a tattoo done by a friend and develops diabetes and hypertension by the age of 30. He is unemployed, intermittently homeless, and has just been arrested for physically and sexually assaulting his girlfriend after she got an abortion he didn't want her to have.

Trauma can be devastating (Box 36-3). Physical injuries from traumatic violence are often life altering. Both children and adults may suffer severe traumatic brain injuries due to violence. Children's brains are particularly vulnerable to physical violence. Babies may suffer blindness, cerebral palsy, severe cognitive impairment, and even death from "shaken baby syndrome."[38] Less visible are the emotional disturbances, psychological scars, and injury to the ability to form and sustain good relationships that result from trauma. Trauma, whether caused by a one-time catastrophic events or chronic, ongoing traumatic events, can shatter one's sense of safety. Trauma that involves interpersonal abuse and violence especially from a family member or partner represents profound human betrayal and has been found to be particularly devastating.

Although all people who experience trauma are altered by it, children are particularly vulnerable to serious lifelong

Box 36-3. Conditions Related to Trauma

- Physical injury and homicide
- Psychiatric illnesses (anxiety, depression, posttraumatic stress disorder [PTSD], complex PTSD [cPTSD], suicidality)
- Chronic illnesses (heart, lung, liver, and other diseases)
- Sexually transmitted infections including HIV
- Sleep disorders
- Unwanted pregnancy and pregnancy at early age
- Childhood learning and behavior problems
- Substance use
- Homelessness
- Premature death (due to poor health, homicide, suicide)
- Future victimization or perpetration of violence

adverse effects of trauma. In order to develop optimally healthy brains, bodies, and relationships, children need stable, nurturing, consistent, and highly attuned relationships with caregivers. Secure and attuned attachments with caregivers allow children to internalize abilities to self-soothe, develop a positive self-image, learn to relate to others with care and love, and to play and explore in ways that promote healthy brain development. Conversely, the developmental life course of children who have been abused and neglected, often by someone who was supposed to be a trustworthy or caregiving figure, is profoundly disturbed.

TOXIC STRESS

Trauma disrupts our optimal health and normal development. The mechanisms through which trauma affects our health are beginning to be elucidated. There is a dynamic, continuous, and interplay between "nature" (our biology) and "nurture" (our environment). Our biology is altered by our experiences, relationships, and other responses to our environment. Positive stress that briefly increases stress hormones but then remits, as when a toddler falls and gets back up or when an adolescent takes a test, is necessary for normal development. Prolonged stress or trauma that overwhelms one's capacity to weather these experiences and is not relieved by a healthy, caring relationship or one's capability to self-soothe is called "toxic stress" or "traumatic stress."

Toxic stress adversely affects our health through autonomic, neuroendocrine, inflammatory, genetic, epigenetic, and behavioral pathways. Cumulative exposure to extreme stress can result in an imbalance in our biological steady state. Persistent activation of stress hormones and other bodily stress-reactive processes can result in pathological biological changes. For example, toxic stress activates the hypothalamic–pituitary–adrenocortical axis and the sympathetic-adrenomedullary system and causes the release of inflammatory mediators.

When toxic stress occurs during the extraordinarily active periods of brain development in childhood and adolescence, it can cause remodeling of the brain's architecture and body's biology in ways that have lasting ill effects throughout the lifespan.[39-41] This brain remodeling results in adverse changes that affect one's ability to learn and make constructive decisions; one's behavior and way of relating; and one's physical and mental health. Prolonged exposure to childhood adversity remodels the areas in the brain that control executive function, addiction, and craving.[41]

Research has focused on epigenetic changes (i.e., changes in the way genes are expressed) in response to toxic stress as one pathway through which trauma can impact health and behavior. Telomeres, the DNA-based caps and protein structures at the chromosome tips, are associated with accelerated aging and later disease.[42] Telomere shortening in response to childhood maltreatment has been studied prospectively: children exposed to multiple forms of abuse at age 5 (exposure to maternal domestic violence, frequent bullying, or physical maltreatment by an adult) were found to have shorter telomeres at age 10 than children who were not maltreated.[43]

Children who have suffered from maltreatment demonstrate many sequelae of trauma or toxic stress that is not ascribed to their root cause. Childhood trauma manifests differently at different developmental stages. Infants may suffer from failure to thrive; school age children may present with attention and learning difficulties; and adolescents may engage in early and risky sexual activity or substance use. Prolonged or repetitive trauma in childhood puts children at risk for life-long psychological and relationship problems. Children and adults who experience traumatic events may suffer from fear, mistrust, a sense of vulnerability, feelings of isolation, and multiple adverse psychological sequelae including insomnia and other sleep disturbances, anxiety disorders, PTSD, substance abuse disorders, and mood disorders. Trauma markedly increases the risk of suicidality in both adolescents and adults.[44]

POSTTRAUMATIC STRESS DISORDER

PTSD is a trauma- and stress-related condition that can occur after exposure to an extremely traumatic event. The lifetime prevalence of PTSD is 7.8% in the United States[45] and varies from .3% to 6.1% in other countries.[46] Certain vulnerable populations who have suffered extraordinarily high burdens of trauma, women living with HIV and incarcerated people, for example, also have extremely high rates of PTSD.[11,47]

The risk of development of PTSD after a traumatic event varies markedly depending upon the type of trauma.

After a natural disaster, for example, only approximately 5% of men developed PTSD. After rape, however, 65% of men and 49.7% of women develop PTSD. Other types of trauma with a high risk of PTSD include combat, childhood neglect, and childhood physical and sexual abuse.[48] Overall, for all traumatic events combined, women seem to develop PTSD at twice the rate that men do, even after accounting for the prevalence and type of trauma exposure.[49] It is now understood that adults, adolescents, children, and even infants can develop PTSD. Although it is not possible to predict exactly who will develop PTSD after a traumatic event, risk factors for developing PTSD include having a prior trauma histories, a family psychiatric history, a perceived life threat from the trauma, poor social support, and peritraumatic emotional responses.[50]

PTSD rarely occurs as the single sequela of trauma and often presents with a "co-occurring" mood disorder or substance use disorder.[48] People who have been exposed to complex and prolonged psychological trauma may develop complete post-traumatic stress disorder (cPTSD), a disorder characterized by adverse changes in the mind, emotions, body, and relationships.[1] People suffering from cPTSD have all of the characteristics of PTSD and also have additional profound disturbances of emotion regulation, a negative self-concept, and interpersonal problems. People with cPTSD are often misdiagnosed as having a personality disorder, especially borderline personality disorder.[51]

IMPACT OF CHILDHOOD TRAUMA AND ADVERSITY

Childhood trauma and adversity are now understood to be the most significant root causes of adulthood disease, often occurring decades later. Adaptive but unhealthy behaviors such as overeating, sexual risk taking, smoking, and alcohol and other substance use are more likely in adults who experienced adversity or toxic stress during childhood. These behaviors contribute greatly to the development of chronic illnesses. Yet, the correlation between childhood adversity and adulthood disease exceeds that explained by the impact of high-risk behaviors, thus supporting the research findings of biological impacts of trauma.[39] In the "ACE study," the ACE scores correlate with both adulthood health risk factors and disease in remarkably consistent and strong, dose–response relationships. Increasing ACE scores are associated with increased risk of adulthood IPV, smoking and the early initiation of smoking, alcoholism and alcohol abuse, increased number of sexual partners and early initiation of sexual activity, adolescent pregnancy, unintended pregnancy, abortion, sexually transmitted diseases, fetal death, depression, suicide attempts, health-related quality of life, ischemic heart disease, chronic obstructive pulmonary disease (COPD), and liver disease. When compared with adults without any ACEs, adults who had four or more ACEs had 12 times the risk of attempting suicide and double the risk of liver disease and COPD.[52]

In England, a prospective, longitudinal study of "ACEs" (defined differently from the Kaiser study) demonstrated a relationship between adverse childhood events and an increased risk of premature mortality.[53] Women with one ACE had a 66% increased risk of premature death and those with two or more ACEs had an 80% increased risk of death as compared with women with no ACEs. Kaiser Permanente and the CDC have developed a model that explains how ACEs lead to early mortality (Figure 36-1).

TRAUMA AND WOMEN LIVING WITH HIV

The impact of trauma on women living with HIV has been particularly well studied. Recent and/or past abuse has been associated with poor health outcomes at each stage of the HIV Care Continuum, including between two and four times the odds of antiretroviral medication failure, faster disease progression, and more hospitalizations.[54] More importantly, HIV/AIDS is rarely the cause of death in women living with HIV who die. Now, deaths among women living with HIV are mostly related to trauma, directly through murders and indirectly through suicide, overdose, and other trauma-related medical conditions.[55]

POSTTRAUMATIC GROWTH

Not all sequelae of trauma are thought to be negative. Posttraumatic growth is defined as "the subjective experience of positive psychological change reported by an individual as result of the struggle with trauma. Examples of positive psychological change are an increased appreciation of life, setting of new life priorities, a sense of increased personal strength, identification of new possibilities, improved closeness of intimate relationships, or positive spiritual change." Interestingly, it is very unclear whether posttraumatic growth has any modulating effect on the negative psychological sequela of trauma. Studies of the relationship between posttraumatic growth and PTSD, depression, and other adjustment problems have conflicting results.[56]

HEALTH-CARE ENVIRONMENTS ARE CHALLENGING FOR TRAUMA SURVIVORS

> Kim is a 40-year-old survivor of childhood sexual abuse perpetrated by her father. Kim has suffered from untreated bouts of severe anxiety and depression ever since she was abused. When she was a 22-year-old, she went to a clinic for a Pap smear. The nurse told her to undress and lie on the exam table with her legs in the stirrups before she met the physician who would do her Pap smear. The physician entered the room, asked her a few quick questions, and then proceeded to do the Pap smear without explaining anything. Kim felt sudden, overwhelming terror, chest tightness, and palpitations.

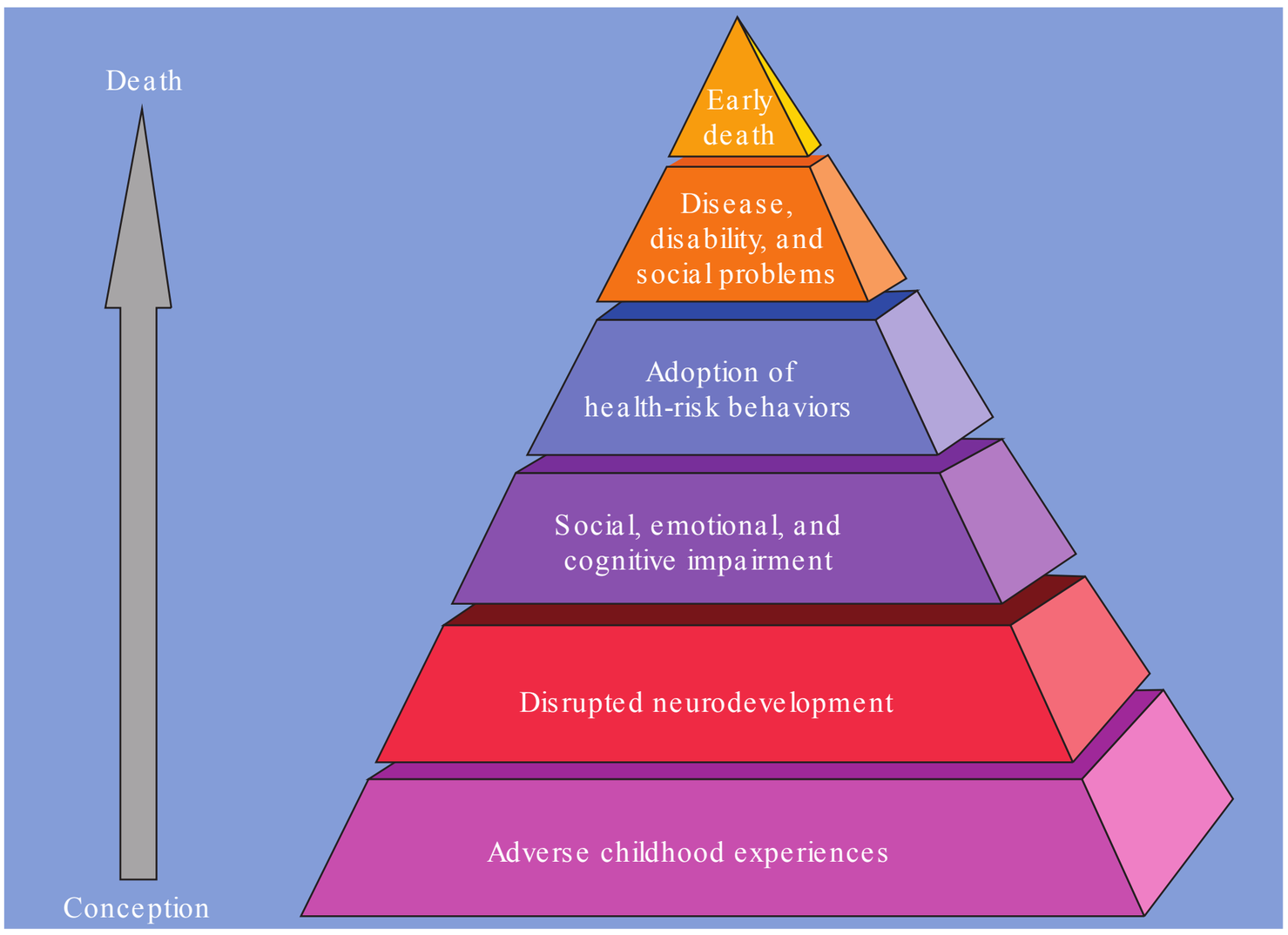


Figure 36-1. Mechanisms by which adverse childhood experiences influence health and well-being throughout the lifespan. (From https://captus.samhsa.gov/prevention-practice/targeted-prevention/adverse-childhood-experiences/1.)

> She says, "I felt like I left my body" and doesn't remember what happened during the visit or how she got home. She never returned for Pap screening. Recently, after many years of very heavy vaginal bleeding, Kim fainted, was brought to the hospital, and diagnosed with advanced cervical cancer.

In health-care settings serving disadvantaged and underserved clients, the proportion of patients who have histories of trauma is extraordinarily high. Survivors of trauma, even in the absence of PTSD, may be consciously and unconsciously "triggered" by sights, smells, sounds, and situations that occur in the health-care setting. Excessive waiting times, invasive physical procedures, the need to undress, the inherent imbalance in power between the patient and the providers, the use of physical restraints, and more may result in retraumatization. Often, patients entering a health-care or treatment setting do not fully comprehend the connection between their heightened emotional state and their history of past trauma. This "triggering" of traumatic memories or sensations may make a treatment setting intolerable to a patient.[57]

A patient who has suffered trauma may act belligerently resulting in being discharged from care, or may experience dissociation from the present moment and not be able to recall important events in his or her medical history and may have problems retaining important health-care instructions. Survivors of childhood or other abuse may react in an overly aggressive or overly submissive manner to authoritarian health-care providers. And many patients with a history of trauma who find the health-care setting intolerable may simply give up altogether and not follow up with appropriate care. Effective treatment for trauma survivors depends upon the health-care setting becoming "trauma informed."

TRAUMA-INFORMED CARE

The principles of trauma-informed care are consistent with patient-centered care approaches. Trauma-informed care has been defined as "a strengths-based service delivery approach that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment" (http://beta.samhsa.gov/samhsaNewsLetter/Volume_22_Number_2/trauma_tip/key_terms.html).

Trauma-specific care refers to the methods used to treat the physical, emotional, relational, and other sequelae of trauma. Multiple trauma-specific interventions have been evaluated and found to improve various patient outcomes.[58] Models of comprehensive trauma-informed care in the health-care setting, though, have not yet been tested to determine whether they improve patient outcomes or provider and staff well-being. Pediatric practices, responding to powerful evidence about how toxic stress harms children, have led efforts to create trauma-informed clinics.[59,60] The American Academy of Pediatrics has developed a "trauma tool kit" available at www.aap.org/traumaguide.

CONCEPTUAL MODEL OF TRAUMA-INFORMED CARE

Experts recently developed a conceptual model of trauma-informed care for adults.[61] Ideally, trauma-informed care creates healing and empowerment for the patient, the patient's family, and the health-care providers and staff, and rests firmly upon a foundation of trauma-informed principles and competencies (Figure 36-2).[62]

The San Francisco Department of Public Health has developed foundational trauma-informed principles and competencies including: trauma understanding, cultural humility and responsiveness, safety and stability, compassion and dependability, collaboration and empowerment, and resilience and recovery (http://www.leapsf.org/pdf/Trauma-Informed-Systems-Initative-2014.pdf).

Trauma Understanding

A trauma-informed clinic or hospital is one in which all providers and staff have been trained to understand trauma and its effects on all of us. All providers and staff understand that almost every single person entering the health-care facility (including each of their coworkers) has experienced some form of hidden trauma. They respect each patient and coworker for her/his strength and resilience in facing adversity. They understand that people's unhealthy ways of relating to others and unhealthy behaviors are often adaptations to traumatic experiences. They understand that our many identities (culture, race/ethnicity, religion, sexual orientation, gender identity, and more) affect our risk of experiencing trauma, our responses to trauma, and the types of support we are able to access when experiencing trauma. Historical and structural trauma that has harmed entire communities and community resiliencies are acknowledged and inform responses to trauma.

Safety and Compassion

Providers and staff work together to create and sustain an atmosphere that is clean, safe, calm, and suffused with compassion. Educational materials about various forms of trauma and programs that assist trauma survivors are prominently displayed in public and private settings like waiting rooms, exam rooms, and bathrooms.

Providers and staff treat patients with respect and a nonjudgmental perspective, emphasize patient strengths and resilience, educate patients and families about trauma, and strive to provide patients with as much control and choice regarding their care as is possible. The health-care team partners with peer advocates who have survived traumatic experiences and are well trained in trauma-informed care. Peer advocates provide examples of resiliency, mentorship about paths to healing, and navigation through treatment options.

Because traumatized patients may be fearful about accessing care, the health-care system does community outreach and case management that extends beyond

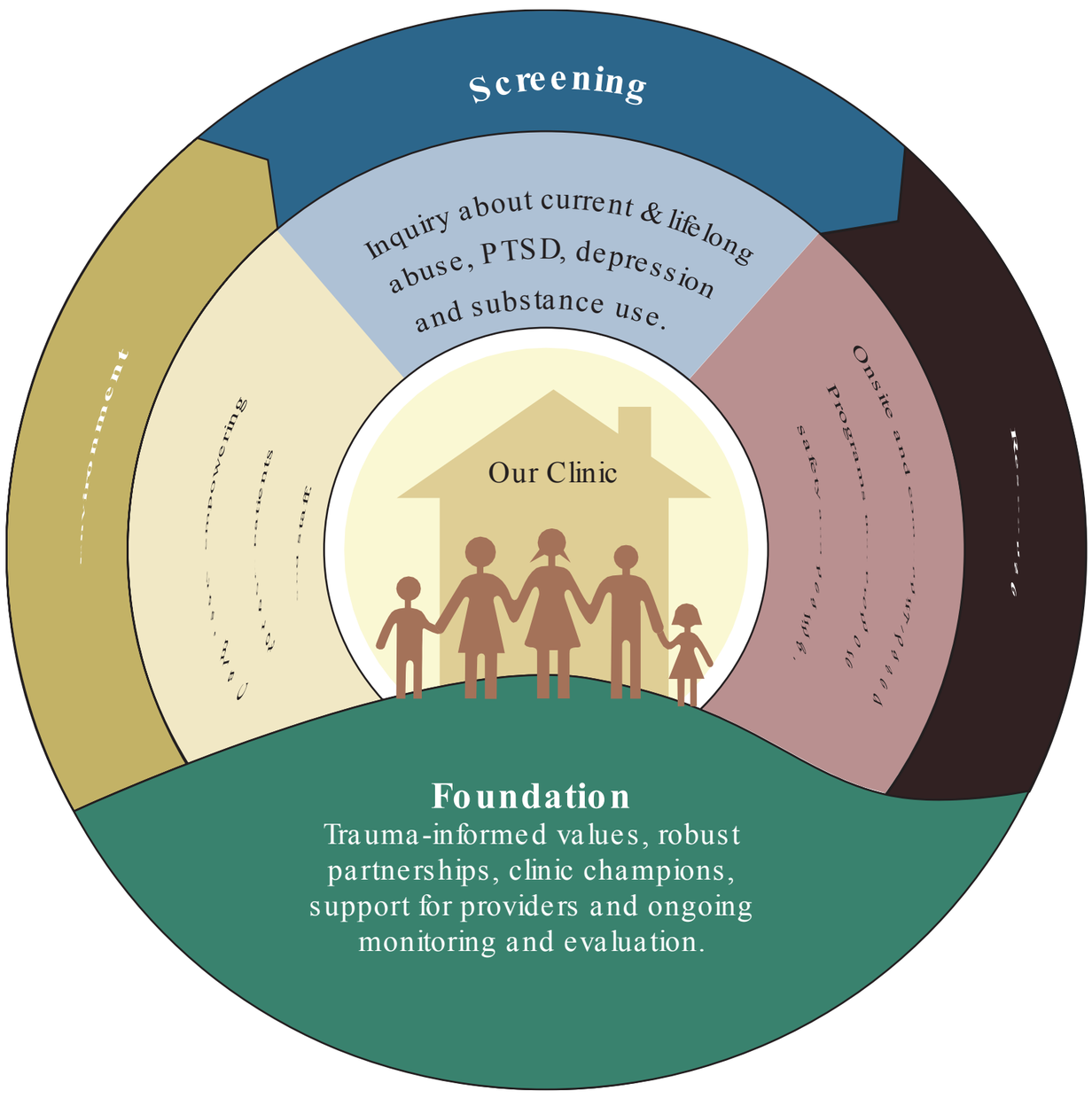


Figure 36-2. A framework for trauma-informed primary care. (From Machtinger EL, Cuca YP, Khanna N, Rose CD, Kimberg LS. From Treatment to Healing: The Promise of Trauma-Informed Primary Care. Womens Health Issues 2015;25:193-197.)

the clinic and hospital walls. The management of the health-care clinic or hospital involves providers and staff in collaborative processes of decision making and treats employees with respect because they understand that highly hierarchical and abusive management practices perpetuate the dynamics of trauma.

Collaboration and Empowerment

In trauma-informed care, trauma is considered an important "root cause" of many emotional, behavioral, physical, and psychological illnesses. When behaviors that are usually stigmatizing, such as depression or substance use, are framed as adaptations to traumatic experience, the patient is offered an opportunity to see herself or himself in a different, more positive light. The health-care team and peer advocates can emphasize the remarkable courage and strength it takes to survive traumatic experiences.

Universal Education About the Effects of Trauma

In trauma-informed care, patients are given universal education about the effects of trauma on health as a safe way to introduce trauma. With proper training and implementation of safeguards, direct and indirect inquiry about trauma and the social determinants leading to trauma are incorporated into team-based care. Patients are offered opportunities to disclose traumatic events and the effects of those experiences on the patient's practical, spiritual, psychological, relational, and physical life course if they choose to do so.

The health-care team incorporates evidence-based screening for various forms of trauma (including interpersonal violence and abuse) in order to enhance patient safety, address the "root causes" of unhealthy behaviors, improve health outcomes, and refer patients to helpful treatment and support options. Even when patients choose not to disclose trauma, they can access treatment options on-site and in the community via facilitated self-referral.

Trauma Treatment Programs

In trauma-informed care, patients and families are introduced to evidence-based trauma treatment programs on-site, through home visits and in the community. Patients who have experienced trauma are offered a wide array of healing experiences and treatments that are developmentally appropriate, evidence based, and culturally attuned. Evidence-based trauma-specific interventions including parent–child therapy and trauma-informed substance use, depression, anxiety, PTSD, and cPTSD treatment are promptly available. Resources that promote increased resiliency are easily accessible, such as vocational training and housing and educational support.

Vicarious Traumatization

In trauma-informed care, particular attention is paid to the personal traumatic experiences of providers and staff and the phenomenon of "vicarious traumatization" or "VT," defined as "the negative transformation in the helper that results from empathic engagement with trauma survivors and their trauma material, combined with a commitment or responsibility to help them."[63] Providers and staff explore how their own traumatic experiences and cultural perspectives have shaped their outlook on relationships and their work. Providers and staff learn how to care for themselves in the moment, so that when they are listening empathically to a patient describe experiences of human cruelty and betrayal and other traumas they may stay as calm as possible. Providers learn to balance maintaining compassion and empathy while not over-identifying with and re-living the patient's experience. Providers and staff also learn how to care for themselves over the long term in order to maintain hope, meaning, and faith in humanity. A safe, calm, well-organized clinical environment that emphasizes respectful, nonhierarchical teamwork and supportive policies and practices supports provider and staff well-being.

ROUTINE SCREENING FOR ABUSE AND TRAUMA

In the United States, screening all women for IPV is required by the Joint Commission on Accreditation of Healthcare (JCAHO) and the Affordable Care Act (ACA) and screening is recommended by the US Preventive Services Task Force (USPSTF). The American Congress of Obstetricians and Gynecologists issued an opinion that all women should be screened for childhood sexual abuse (in addition to the required IPV screening) and have provided guidance on how to do this (see Chapter 35).[64] Direct and routine screening of all adults for earlier child abuse and for other types of traumatic experiences in the context of primary care and specialty care (other than psychiatry) has not been adequately studied.

There are no well-validated and reliable tools for screening of asymptomatic children and their caregivers for the abuse and neglect of children. In 2004, the USPSTF found insufficient evidence to recommend for or against the routine screening of parents or caregivers for the abuse and neglect of children; they did find evidence that primary child abuse prevention programs offered in the health-care setting are effective.[65]

Despite a lack of research, clinics and providers are rapidly adopting these practices and are incorporating some form of ACEs screening for all patients.[59,60] Others advise a universal education approach (rather than routine screening) as a safer option due to concerns over the potential adverse effects of screening for lifetime trauma including stigmatizing patients and focusing on pathology rather than resilience.[66] Some practices are also piloting "resilience questionnaires" (see http://acestoohigh.com/2014/07/29/to-prevent-childhood-trauma-pediatricians-screen-children-and-their-parentsand-sometimes-just-parents/#more-3327).

> Lorraine's mother abused methamphetamines and dated a series of highly abusive men, one of whom raped Lorraine repeatedly when she was 12. As a teenager, she began drinking alcohol and binge eating to numb her emotional pain. Lorraine presents to primary care, smelling of alcohol. She is morbidly obese. Her blood pressure is 190/98. She wants her provider to prescribe something "to help me fall asleep".

INQUIRY ABOUT ABUSE AND TRAUMA BASED ON "INDICATOR" CONDITIONS

In patients with relationship difficulties, behavioral problems, emotional distress, mental health disorders including depression, anxiety, PTSD, cPTSD, suicidality, sleep disorders, substance use disorders, chronic pain, a current or past injury, sexually transmitted infections, or the early onset and high burden of chronic diseases, a history of past traumatic experiences is highly ranked in the differential diagnosis. In safety-net clinics and hospitals, these indicator conditions are present in most patients.

There is inadequate study and guidance on how best to inquire about past traumatic experiences in both children and adults who have conditions that may be sequelae of trauma. Standardized tools for trauma screening exist, yet are cumbersome to use. Trauma exposure checklists for adults (http://www.ptsd.va.gov/professional/assessment/te-measures/chart-trauma-exposure.asp) and children (http://www.ptsd.va.gov/professional/assessment/child/child-measures.asp) are used in some settings. There is evidence that many patients prefer to be screened for sensitive topics such as IPV through "audio computer-assisted self-interview" (ACASI) which can be done with audio assistance in various languages in order to provide screening and, even, individualized to low literacy patients (see Chapter 35).

SCREENING FOR THE PSYCHOLOGICAL SEQUELAE OF TRAUMA

Because trauma results in an increased prevalence of substance use, depression, anxiety, and PTSD, screening for these conditions is warranted in patients who have experienced trauma or are at very high risk of trauma. Many patients with PTSD go unrecognized and experience delays in receiving treatment. In a nationally representative survey of US adults, only 7.1% of patients with PTSD talked to a physician or other professional about their symptoms within the first year of experiencing them, and the median time between onset of PTSD symptoms and receipt of mental health treatment was 12.1 years.[67] Screening for PTSD in primary care may prevent delays in diagnosis and mental health treatment and should certainly be done when trauma is discovered or when the patient complains of symptoms typical of PTSD. Several brief questionnaires have been validated in primary care settings. A study comparing four PTSD screening questionnaires in a family medicine clinic population found the primary care PTSD (PC-PTSD) screen had the best test characteristics[68] (http://www.ptsd.va.gov/professional/assessment/DSM_5_Validated_Measures.asp).

TRAUMA-SPECIFIC INTERVENTIONS

> Lorraine's primary care physician makes several empathic statements in their first visits. (See Core Competency). During her third primary care visit, Lorraine reveals that she was sexually assaulted as a child. She shares that she has felt horribly ashamed for decades about this experience and her drinking. Lorraine's provider responds: "No wonder you started drinking when you were 11. It was so important for you to find a way to cope with an impossible and painful situation. We all deserve to be treated well. I am so sorry you were hurt as a child." After discussing coping techniques, Lorraine accepts a referral to a trauma-informed program that helps women suffering from trauma, mental health problems, and substance addiction heal.

Explaining that substance use, overeating, self-harm, or other injurious behaviors are common coping techniques in response to trauma can be a healing experience for patients. Emphasizing the extraordinary strength that a patient has demonstrated in coping with trauma can be empowering. Practicing calming breathing exercises with a patient when discussing trauma and limiting trauma history appropriately to provide a patient with an environment that prioritizes emotional safety is helpful. Focusing on coping techniques, resiliency, and positive support rather than delving deeply into traumatic details in the primary care setting allows patients to feel more in control.

The Women with Co-Occurring Disorders Study (WCDS) demonstrated that trauma-informed care in mental health and substance use settings was more beneficial to patients than usual care.

SAMHSA maintains a National Registry of Evidence-based Programs and Practices (NREPP) that is continually updated and currently describes 37 trauma-related evidence-based interventions.[69] These treatment programs are effective in treating various poor health and relationship outcomes related to trauma. Certainly, the mental health sequelae of trauma, including PTSD, are treatable. A systematic review found that psychological therapies such as exposure therapy, cognitive processing therapy, cognitive behavioral therapy–mixed therapies, eye movement desensitization and reprocessing, and narrative exposure therapy were effective for improving PTSD symptoms and/or achieving loss of

diagnosis. The effect sizes for these treatments were quite large. Medications (including fluoxetine, paroxetine, sertraline, topiramate, and venlafaxine) have also been found to be effective in reducing PTSD symptoms (although the effect sizes are smaller).[70]

Helping patients suffering from complex traumatic stress disorders is naturally more challenging than treating PTSD. Survivors of complex trauma who have cPTSD not only have symptoms related to PTSD but also have had their development utterly disrupted resulting in problems regulating their emotions, a negative self-image, and impaired relationships with others. Thus, it is essential for the health-care provider to maintain a calm, compassionate demeanor and model a healthy relationship with appropriate relationship boundaries when caring for a patient with cPTSD. Especially in the context of brief primary care visits, helping a patient heal from complex trauma can be daunting. Fortunately, promising treatments for cPTSD are being developed.[71] Mindfulness meditation, yoga, and other somatic and creative therapies for the psychological sequelae of trauma also provide hope for healing.[72,73]

The evidence for the treatment of PTSD notwithstanding, there is generally a lack of research on interventions to address the physical, mental health, and practical sequelae of trauma in highly disadvantaged urban communities. Urban underserved victims of violent crime may need urgent help with finding safe housing, food, medical service, and financial assistance. Stigma about mental health treatment, poverty, and lack of access to trauma treatment services influence outcomes for low income and minority victims of crime. Pioneering models of care to address the full panoply of issues confronting trauma victims from underserved communities emphasize assertive outreach, engagement in treatment, and practical assistance in order to increase access, adherence, and efficacy of treatment. In a mental health trauma center, this model resulted in patients receiving trauma treatment services six times more often than usual community services.[9] Trauma centers in urban environments in the United States also have been pioneering new models of care for victims of community violence. These models of care are based on trauma-informed principles and have been proven to be both effective in reducing violence recidivism as well as cost-effective.[74]

PREVENTION—REDUCING TRAUMA TO ACHIEVE HEALTH EQUITY

Since the biological and psychological sequelae of interpersonal violence are a root cause of most of the leading causes of morbidity and mortality worldwide, eliminating preventable forms of trauma such as abuse and neglect holds great promise in achieving health equity.[75] Treating the sequelae of lifelong abuse (such as substance addiction and mental illness) in parents and caregivers prevents exposure to adversity and trauma for the next generation. Because IPV is so highly associated with child abuse and witnessing IPV is so harmful to children, preventing and reducing IPV is a primary prevention strategy for reducing childhood trauma, abuse, and neglect.

Primary prevention evidence-based programs to eliminate childhood abuse and neglect include specific evidence-based home visitation programs (based on the Nurse–Family Partnership model) for first time expectant mothers in families at greater risk of having child abuse and neglect[76]; the Positive Parenting Program (Triple P); Safe Environment for Every Kid (SEEK); and the Strengthening Families initiatives.[65,77] Prevention programs designed to eliminate the many intersecting and interrelated forms of violence show great promise.[13,75]

CONCLUSION

Worldwide, trauma is a leading cause of morbidity and mortality. Traumatic experiences are disruptive and overwhelm a person's ability to adapt to the stresses and vicissitudes of life. The impacts of trauma are dependent on individual and community vulnerabilities, resources, and protective factors. Trauma, especially in childhood, is a root cause of adult disease and high-risk behaviors. Trauma disproportionately affects the most vulnerable people and populations. Addressing trauma in the health-care setting has the potential to improve health, decrease suffering, and promote the achievement of health equity. Health-care providers have a uniquely influential role to play in implementing trauma-informed care and in recommending evidence-based health care community and societal trauma prevention programs and policies. Violence prevention, poverty elimination, education promotion, hunger prevention, homelessness prevention, and other strategies that eliminate social disparities all contribute to the prevention of life-altering trauma and the achievement of health equity.

- Trauma is a nearly universal human experience and is more common in vulnerable populations.
- Childhood trauma results in later adulthood high-risk behaviors, and disease.
- Individual, family, community, and societal risk and protective factors as well as resiliency affect the prevalence and experience of all types of violence and trauma.
- Trauma-informed care holds promise for improving health outcomes and helping to break the cycle of intergenerational transmission of trauma.

Skills in Trauma-Informed Care: Caring for Survivors of Lifetime Abuse

Four C's:

Calm Pay attention to how you are feeling while caring for the patient. Breathe and calm yourself to help model and promote calmness for the patient and care for yourself.

Contain Ask the level of detail of trauma history that will allow patient to maintain emotional and physical safety, respect the time frame of your interaction, and will allow you to offer patients further treatment.

Care Remember to emphasize, for patient and yourself, good self-care and compassion.

Cope Remember to emphasize, for patient and yourself, coping skills to build upon strength, resiliency, and hope.

Calm

- Keep questions simple and nonjudgmental.
- Many patients may be more comfortable revealing details of trauma on questionnaire/computer touch screen than in face-to-face interview.
- Screen for depression, PTSD, substance use, risk-taking behaviors (use the PHQ-9, PC-PTSD).
- Learn and practice breathing and "grounding" techniques during the visit for yourself and for the patient who is anxious or distressed.

Remember—all of us have histories of traumatic events in our lives. Trauma that you have experienced yourself can sometimes make hearing about trauma harder or can sometimes help you understand trauma, strength, and resiliency in a more personal way.

Contain: Limit trauma history detail to maintain safety:

- The goal of taking a trauma history or providing education about trauma is to improve safety, well-being, health, and relationships. Thus, for example, pushing a patient who feels that her/his life will be endangered by revelation of abuse or trauma would be unethical and dangerous.
- Most situations involving taking a trauma history in the context of primary care are more nuanced than this and involve patient and provider decisions about the level of trauma history detail appropriate to share in a particular situation.
- Most patients with a trauma history will not reveal their history without your inquiring. Yet, once you do inquire, it can be challenging for the patient and provider to judge what level of detail is optimal to reveal. It is quite possible that a patient (especially one with a history of complex childhood trauma) may go into a level detail that could lead to destabilization during or after the visit.

Methods to contain "trauma history telling" with patients:

- First, remember that one of the most important thing you are doing is modeling a healthy, safe relationship—and that it is healthy to know if someone is trustworthy prior to revealing a great deal of vulnerability (even with health-care providers who may be "assumed" to be trustworthy).
- "It is important that you explore this with a therapist who understands how to help people who have experienced trauma, so that you only go into as much detail as you can handle without feeling too exposed or too out of control."
- If patient hints at a childhood trauma history in a visit . . . ." I hear that something difficult might have happened when you were a child. In the future, when we know each other better, I am open to talking to you about this in order to help you get help."
- "We have just met and don't know each other well yet. So, it is important that we get to know each other over time and figure out together how to help you while also keeping you safe emotionally."
- For early in clinician–patient relationship or with distressed patient: "In my experience, when a patient tells me that he began drinking at age 12, it is often because he was experiencing very difficult things during childhood. We are just meeting each other for the first time today, so we don't need to go into those details right now. I do want you to know that I am open to discussing those things in the future or referring you to a counselor who specializes in trauma treatment if you think that would be helpful."
- "I am going to ask you to pause and check in with yourself. It is important that you only discuss the level of detail about your traumatic experience that will allow you to feel safe, even after this visit is over."
- Practice breathing and "grounding" exercises at the beginning of visit and at the end of visit with the patient to help the patient focus on developing skills to self-soothe (Calm).
- "Let's slow down and do some deep breathing together. Let's sink into our chairs and feel how solid the earth is beneath us.

Care: Demonstrate compassion and caring for patient, while caring for self:

Share messages of support:

- "I am so sorry this happened to you." "We all deserve to be treated well." "I am sorry you were hurt as a child." "It can be very hard to learn to take good care of yourself when you were hurt as a child."
- De-stigmatize adverse coping behaviors:
- "No wonder you started drinking when you were 10. It was so important for you to find a way to cope with an impossible and painful situation."

Cope: Emphasize resiliency, coping skills, positive relationships, and patient's wisdom.

- Listen carefully for patient's own words of wisdom and good self-advice and repeat those back to patient.
- Counter patient's negative self-messages respectfully.
- Positive relationships with people or pets demonstrate to patient that she/he is worthy of love. Remind the patient of any caring relationships.

- Model healthy, caring, and reliable relationship in patient–provider relationship.
- Messages:
  - "Look at how strong you are to survive such difficult circumstances."
  - "I am so glad you had the strength to reach out for help today. That was brave of you."
  - "I hear how loved you felt by your favorite aunt. It sounds like she was very important in your life."

Practical techniques:

- The "after visit" written summary for patient: Include patient's own words of advice to herself/himself and read them aloud to patient. "You told yourself: 'I think if I take a walk around the block when I feel nervous I might not need to drink as much.'"
- "Solutions list": in medical records, rather than making only a "Problem list," add a solutions list to the record that includes all the patient's positive coping techniques so that each member of the health-care team can emphasize and reinforce patient's preferred coping techniques.
- If patient is distressed during visit, practice grounding and calming techniques and, also, ask patient: "When you feel this badly, what do you usually do to cope?" This is important in order to help the patient pull herself/himself back together before leaving. Otherwise, the patient is left with associating coming to see you with a feeling of lack of control. So, help the patient remember her/his strengths.

Self-care tips:

- In the moment: breathing (SLOW it down), relax tensed muscles, "grounding"—(feel your weight sink into the chair, floor, and earth). What else works for you?
- Between each patient: Send the patient you just saw a compassionate blessing or wish as you take a deep breath ("I wish you peace"), really pay attention when you wash your hands and feel yourself "let go" before you move on to the next patient—again with deep breathing and grounding.
- After you are done seeing patients: Practice resting, escaping, playing, creating hope, and meaning with healthy practices that foster connection to self, others, nature, or whatever else feels healing for you. Monitor yourself and learn more about vicarious traumatization.
- For students: It is fine if you need to (calmly) excuse yourself and tell patient. "I would like to get my teacher to help us discuss this as safely as possible." (And for more experienced providers who work in settings with psychological providers on-site, it may be possible to do this when needed as well.)

DISCUSSION QUESTIONS

1. Discuss how minority status (race/ethnicity, religion, sexual orientation, gender identity, and other factors) affects individual or community risk for violence and trauma.
2. Discuss ways in which you could introduce the topic of trauma and its effects with adult patients and with children and parents in pediatric practice.
3. Discuss ways in which you could approach both trauma and vicarious traumatization from a "resiliency or strength-based" framework. How would this framework change the ways you care for patients and yourself?

RESOURCES

Harvard Center for the Developing Child has videos to explain core concepts in development and their disruption by trauma: http://developingchild.harvard.edu/index.php/resources/multimedia/#videos.

TED talk by Nadine Burke Harris on childhood trauma and its effects on health across the lifespan: http://www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime?language=en.

ACES too high Web site has links to many videos about ACES and trauma: http://acestoohigh.com/resources/.

National Center for PTSD has many videos about PTSD, and treatment for PTSD: http://www.ptsd.va.gov/professional/materials/videos/index.asp.

Centers for Disease Control online course on violence prevention: http://vetoviolence.cdc.gov/apps/pop/prevention-main.html.

Useful Web sites:

The Centers for Disease Control has extensive information, resources, and numerous violence prevention projects described at: http://www.cdc.gov/ViolencePrevention/index.html.

ACES too high is a website devoted to sharing national and international information about ACES, trauma, and innovative community solutions to preventing and ameliorating ACES: www.acestoohigh.com.

SAMHSA (Substance Abuse and Mental Health Services Administration) describes foundational principles of trauma-informed systems and care at: http://www.samhsa.gov/nctic/trauma-interventions.

National Center for PTSD site has numerous helpful resources on understanding and treating PTSD (see "For Professionals" section: http://www.ptsd.va.gov/.

National Child Traumatic Stress Network has extensive information and resources on trauma and children and families: http://nctsn.org/.

Useful Books:

Trauma and Recovery: The Aftermath of Violence—From Domestic Abuse to Political Terror by Judith Herman.

The Boy Who Was Raised as a Dog: And Other Stories from a Child Psychiatrist's Notebook—What Traumatized Children Can Teach Us About Loss, Love, and Healing by Bruce Perry and Maia Szalavitz.

The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma by Bessel Van der Kolk.

Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others by Laura Van Dernoot Lipsky with Connie Burk.

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Dedicated to Patricia Van Horn, PhD, JD

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Chapter 37

Obesity as a Clinical and Social Problem

Ann Smith Barnes, MD, MPH, Marisa Rogers, MD, MPH, and Cam-Tu Tran, MD, MS

Objectives

- Define obesity.
- Describe the populations most affected by obesity.
- Describe the health consequences of obesity.
- Discuss the difficulties with losing weight, including patient and health-care provider challenges.
- Suggest ways for health-care providers to discuss weight loss with patients.
- Describe strategies for weight loss.

Esmeralda, a 15-year-old girl, requests a written excuse to skip school physical education classes. Her body mass index (BMI) of 32 reveals that she is in the highest weight category for girls her age. She often skips breakfast and eats most meals in front of the television. Her family members are also obese and have type II diabetes.

Worldwide young and old are being affected by obesity and its complications. Indeed, the obesity "epidemic" may be one of the most significant challenges to global, as well as national health. Paradoxically, poor families are particularly affected because of coexisting undernutrition, lack of resources to eat healthily, and inadequate venues for exercise.

Tackling the obesity epidemic will be not an easy feat because its causes are complex–bridging societal issues (such as governmental subsidies of high caloric food), and personal ones (how active people are). Although health-care providers need to be engaged in the wider public health and community efforts addressing obesity, helping patients as they strive to lose weight or suffer from its consequences remains equally important. This chapter discusses both the challenges and strategies of addressing obesity.

DEFINITIONS OF OBESITY

The most widely used classification system for obesity–an abnormal accumulation of body fat–in adults is the body mass index (BMI). The BMI estimates the amount of body fat through a calculation that adjusts weight for height (see "Resources" for online BMI calculator). A normal adult BMI is between 18.5 and 24.9. BMIs between 25 and 29.9 indicate overweight, a BMI greater than 30 indicates obesity, and a BMI greater than 40 indicates extreme obesity. Although health implications of BMI cutoffs vary across ethnic groups,[1] it is accepted that increasing BMI is associated with an increased risk of death from cancers and cardiovascular disease. Obesity was most strongly associated with an increased risk of death among never smokers who had no history of disease.[2,3]

BMI for children, unlike adults, is both age and gender specific because children's bodies change dramatically

Box 37-1. Classification System for Obesity

Classification	Body Mass Index for Adults	Body Mass Index for Children
Underweight	<18.5	<5th percentile
Healthy weight	18.5–24.9	5th percentile to <85th percentile
Overweight	25–29.9	85th percentile to <95th percentile
Obesity	>30	>95th percentile

as they grow, and these changes differ between boys and girls. Terminology for classifying BMI in children has changed and now the language is more consistent with the adult classification (Box 37-1).[4] Because in older adolescents a BMI of 95th percentile is higher than the adult cut point of 30 kg/m^2, obesity in this population is defined as BMI > 95 percentile or BMI > 30 kg/m^2, whichever is lower.[4]

In adults, the waist circumference–the body circumference measured at the level of the superior iliac crest–is another measurement that, some argue, better explains obesity-related health risk. Increased waist circumference, a measure of central adiposity, has been shown to be a marker for increased risk even in persons of normal weight. A waist circumference greater than 40 inches in men, and 35 inches in women is considered abnormal and increases the risk of developing hypertension, dyslipidemia, and metabolic syndrome.[5]

EPIDEMIOLOGY OF OBESITY

Between 1980 and 2013, the prevalence of overweight and obese people worldwide rose by 27.5% in adults and 47.1% in children. Sixty-two percent of the world's obese people live in developing countries. In 2013, the United States had the highest proportion of obese people, 13% of the world's total.[6]

The number of overweight and obese people in the United States has significantly increased in recent decades (Figure 37-1). In 2011 to 2012, 68.5% of adults were either overweight or obese. Of these, 34.9% of adults were obese and 6.4% had grade 3 obesity with a BMI ≥40.[7] Approximately 17% of children and adolescents aged 2–19 years are obese. In general, the highest rates of obesity are found in Latinos and African Americans as well as in populations (particularly females) with less education and lower incomes.[7,8]

Unfortunately, obesity prevalence rates have not substantially decreased in the past decade. The prevalence of obesity in women 60 years or older has actually increased.[7] An exception to this has been seen in young children with a decrease in obesity and extreme obesity in low-income

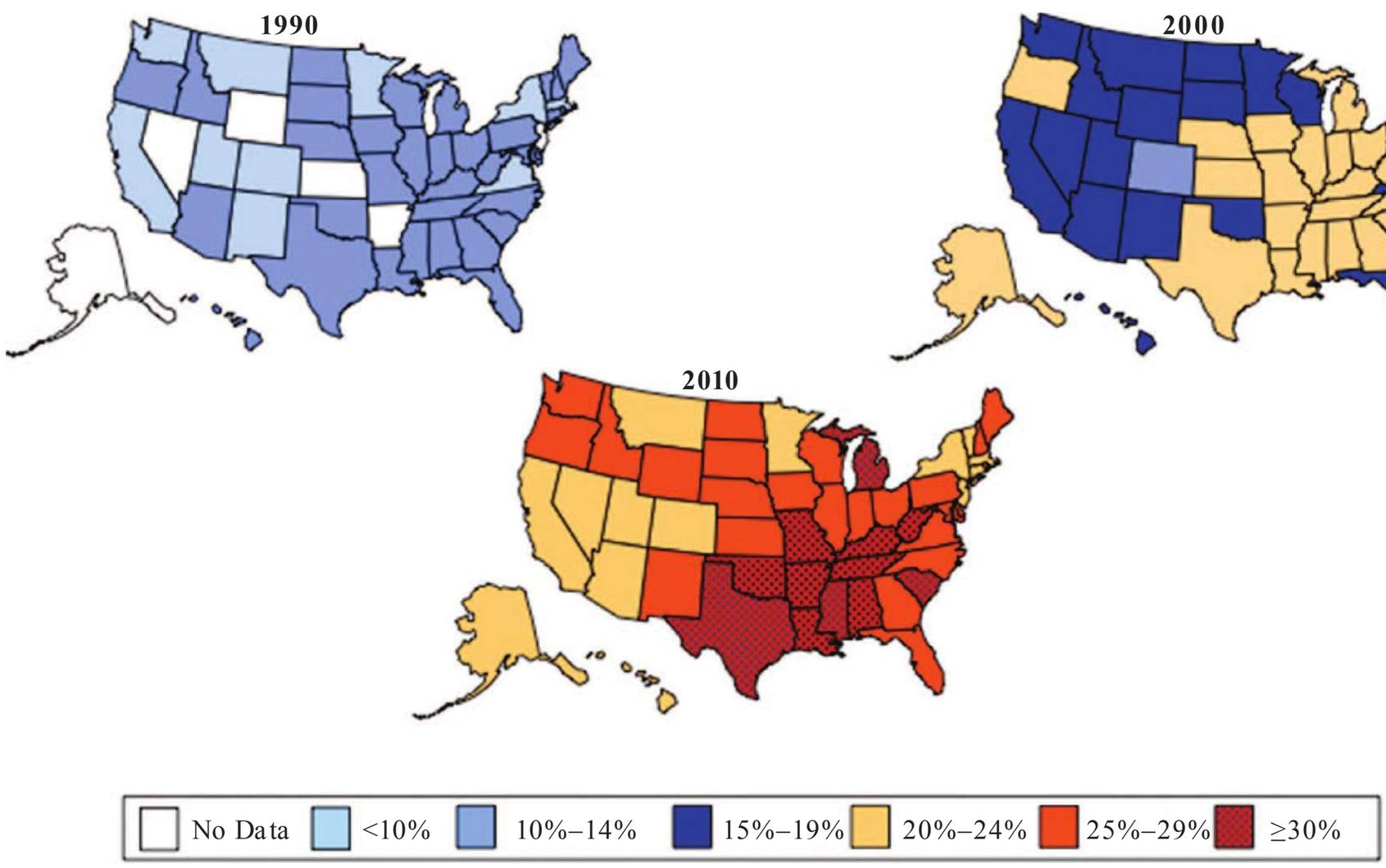


Figure 37-1. Obesity trends among US adults: 1990, 2000, 2010. Data from the Behavioral Risk Factor Surveillance System (1990, 2000, 2010) for BMI ≥ 30, or about 30 lb overweight for 5'4" person. (Source: Behavioral Risk Factor Surveillance System, CDC. Accessed July 6, 2014. Available at: http://www.cdc.gov/obesity/downloads/obesity_trends_2010.ppt.)

children aged 2–4 from 2003 to 2010.[9] These declines were seen in all ethnic groups except American Indians/Alaska Natives. An overall decline is further supported by data showing a 40% decrease in obesity in children aged 2–5 from 2003–2004 to 2011–2012.[7] Reasons for these declines are unclear, but possibilities include increased breastfeeding and decreased consumption of sugary beverages. It is also unclear if this finding will persist with aging.

The economic impact of obesity is substantial. Direct medical spending for diagnosis and treatment has been estimated at up to $147 billion a year in the United States.[10] This does not include the indirect costs of income lost from decreased productivity, disability, absenteeism, and premature mortality, which when totaled are in excess of $200 billion annually.[10,11]

HEALTH CONSEQUENCES OF OBESITY

The health consequences of obesity for both adults and children are significant (Table 37-1). Complications such as hypertension, diabetes, elevated cholesterol levels, and sleep apnea increase the risk of cardiovascular disease, which remains the leading cause of death in both men and women. Not surprisingly, those with the highest rates of obesity suffer from the highest rates of these cardiovascular diseases as well.[12] The same trend even extends to children. For example, nearly half of the newly diagnosed diabetes cases in pediatric populations are type 2 diabetes. This increase is attributable to increasing rates of obesity in children and is highest in African Americans, Mexican Americans, and Native Americans.[13] Other complications of obesity, such as osteoarthritis or depression, may not be as life threatening, but may cause significant incapacity. Arthritis is the most common cause of disability in the United States.

Some of the health consequences of obesity can be mitigated by physical fitness. Those who are obese but physically fit have better mortality rates than their sedentary counterparts. However, both groups have mortality rates greater than individuals who are physically fit and not obese.[14,15] Therefore, patients and health-care providers should note that although physical activity is beneficial, it is not a substitute for weight loss.

Table 37-1. Health Consequences of Obesity in Children and Adults

Organ System	Diagnosis
Cardiovascular	Atrial fibrillation
	Coronary heart disease
	Dyslipidemia
	Heart failure
	Hypertension
	Stroke
	Venous thrombosis
Dermatologic	Acanthosis nigricans
	Furunculosis
	Hidradenitis suppurativa
	Intertrigo
Endocrine	Diabetes/Impaired glucose tolerance
	Hyperandrogenism
	Metabolic syndrome
Gastrointestinal	Fatty liver
	Gallstones
	GERD
Musculoskeletal	Gout
	Osteoarthritis
	Slipped capital femoral epiphysis
Oncologic	Variety of cancers
Pulmonary	Obesity hypoventilation
	Obstructive sleep apnea
Psychological	Anxiety
	Depression

LOSING WEIGHT IS HARD TO DO

> Esmeralda's mother works two sedentary jobs. She has failed at multiple attempts to lose weight. The family eats cheap, fatty, high-calorie food. No one in the family feels they have the money, time, or energy to exercise.

PATIENT CHALLENGES

Diet

The battle to lose weight is often thwarted by lack of time to prepare food at home and the resources to make healthy choices. Eating out at restaurants and eating prepared foods have become common and perhaps necessary as women exchanged housework for paid labor. According to the Department of Labor, among families with children, 59% of these families have dual-income parents; and among single-women head of households, the mothers are employed in 67% of these households.[16] The National Restaurant Association reported that the total restaurant industry sales increased from $42.8 billion in 1970 to $586.7 billion in 2010. In 1950, 25% of all food spending was on food away from home, by 2014, this share rose to 47% of household food budget.[17]

Both larger portion sizes and poorer nutritional quality of food prepared or consumed outside the home encourage greater calorie and fat consumption than home-cooked foods. Portion sizes have been increasing in both prepackaged, ready-to-eat products and at restaurants. Overconsumption is fueled by these larger sizes marketed as providing more for your money.

In addition, increasing evidence suggests an important role for the microbiome in the metabolism of energy and has led to alternative theories regarding the role of the changing gut microbiome in the global obesity epidemic.[18]

Food insecurity, not having regular access to quality foods or having interruptions in eating patterns or unplanned reduction in food intake, is also linked to obesity.[19,20] Families that are food insecure are more likely to skip meals or eat unbalanced meals which hampers healthy weight management.

Food Prices

Food prices influence food consumption. In the United States, income is associated with the type of food consumed, not necessarily the quantity.[21] Calorie-dense foods such as sodas, fruit drinks, and snack foods are inexpensive. Government subsidies favoring corn syrup and sugar production underlie some of these price differences. Healthier foods, such as fruits and vegetables, are sold more frequently in grocery stores, which often are lacking in low-income neighborhoods.[22] Higher cost, limited cooking facilities, perceived ability to satisfy hunger, and short shelf-life of fresh foods can discourage purchase of fruits and vegetables in low socioeconomic groups.[23,24]

Physical Activity

Lack of physical activity hampers efforts at weight control and health maintenance. Long work hours, multiple shifts, increasing time devoted to sedentary behaviors such as television viewing and other media (videos and computers) have been cited as important contributors to the decline in physical activity. Less than one-third of young people meet national recommendations of engaging in physical activity at least 60 minutes each day. Rates are worse among ethnic minority groups, specifically Blacks and Hispanics.[25] According to the Centers for Disease Control and Prevention (CDC), fewer than half (48%) of US adults meet the current physical activity recommendations of 150 minutes of moderate physical activity each week. Again, rates are lower in Black and Hispanic populations as well as in groups of lower socioeconomic status and educational attainment.[26]

ENVIRONMENTAL BARRIERS

Watching television is problematic not only because it is a sedentary activity but also television and radio advertisements highlight quick and easy access to food that is already prepared and of low nutritional value.[27] Children in particular are targeted for advertising–even in schools. Some school districts, in search of extra revenue, have contracted with soft drink companies who provide service vending machines throughout the school district. Some schools have eliminated recess and physical education, decreasing children's daily physical activity. Adults do not fare much better, as long workdays and increasing family demands serve as barriers to regular exercise.

Low-income urban neighborhoods impose other impediments to healthy lifestyles as well. The dearth of grocery stores (food deserts) offering fresh produce and lean meat and plethora of fast food restaurants and convenience stores (food swamps) encourage high-fat, low-fiber diets. Ability to exercise may be compromised by insufficient playgrounds, and parks and trails for walking or biking. Existing areas may not be perceived to be safe. Major fitness centers rarely open exercise facilities in low-income areas, and their membership costs are expensive in most cases.

CULTURAL NORMS

Patients' motivation to lose weight is also influenced by cultural norms and expectations. Many studies have demonstrated that African Americans and some Latinos are more accepting of a larger body size than whites and Asian Americans.[28-34] Consequently, some obese women may not recognize themselves as having a weight problem[35]–this misperception in turn decreases their awareness of disease risk. Additionally, tolerance of larger adult sizes may have an impact on parental recognition of excess weight in children. A meta-analysis of parental estimation of weight status in children demonstrated that 51% of parents underestimate their overweight or obese children's weight. This underestimation is strongly influenced by parental weight status.[36]

The impact of body-shape perceptions is also evident in minority women during childbearing years. It is widely accepted that gestational weight gain affects postpartum weight retention and risk for obesity. Certain demographic groups are at greater risk for excessive gestational weight gain. These include women of low socioeconomic strata, low educational attainment, and African-American ethnicity.[37] In a focus group study by Groth et al,[37] low-income African-American women were accepting of excessive gestational weight gain and associated it with having a healthy infant.

The role of food in many cultures also can have an enormous impact on diet, and subsequently weight control. In focus groups with mothers from low-socioeconomic strata, they admitted to using sweets to bribe their children or reward good behavior and to encouraging them to eat more even when they were full.[38] The use of food as reward, bribe, or pacifier and the notion of "cleaning the plate" are issues that need to be addressed in discussions of diet because they relate to healthful eating within families.

Interventions designed to help vulnerable populations with weight control will need to consider and address cultural norms and practices related to weight and body size. Focus on "healthy eating" and "active living" instead of obesity and weight loss may be more effective approaches for educating and engaging culturally diverse groups.

DISCRIMINATION BASED ON WEIGHT

Research of obese people's experiences suggests that their weight has contributed to negative treatment by strangers

and friends, at job interviews, in the work place, in social settings, at exercise facilities, and by health-care providers.[39-41] Many of the same groups that suffer discrimination based on race, socioeconomic status, and education are more likely to be obese, and consequently suffer an inordinate amount of prejudice.

It is important to acknowledge that subtle forms of discrimination exist in the health-care setting (scales that do not weigh individuals over 300 pounds, chairs with arm rests that are too narrow for obese patients, blood pressure cuffs that are too small for proper measurements). In addition, health-care providers often are guilty of blaming the obese patient for their weight problems and rarely consider the environmental, economic, and social influences on the weight of their patients.[42] Obese patients may feel that health-care providers are not genuinely concerned about them or their health when simple courtesies are neglected. The feeling of second-class treatment or being blamed for a medical problem can negatively affect a person's interest in discussing weight loss with a provider. Recognizing and discussing an obese patient's discomfort in the medical setting can open lines of communication and foster trust relating to all health issues, including weight.

INTERNATIONAL POPULATIONS

Once considered a problem of wealthy nations, obesity rates are on the rise in low- and middle-income countries, particularly in urban areas. More than 50% of the 671 million obese individuals in the world live in 10 countries: the United States, China, India, Russia, Brazil, Mexico, Egypt, Germany, Pakistan, and Indonesia.[6]

The worldwide causes of obesity are similar to those in the United States–an increase in calorie-dense food and decrease in physical activity. Rising incomes in some countries have increased access to high-fat calorically dense foods. Additional factors related to urbanization, globalization, and modernization such as increased television viewing, eating outside of the home, and shifts in agricultural work to service and manufacturing industries have contributed as well. The health consequences of obesity are similar to those seen in the US populations, but many countries are doubly challenged combating complications of obesity as well as those of infectious disease and malnutrition. With increases in obesity driving concomitant increases in diabetes, certain infectious risks, such as those for tuberculosis, may also increase. Unfortunately, the resultant economic burden often falls on countries ill prepared to deal with it.

HEALTH-CARE PROVIDER CHALLENGES

Obesity is a preventable disease and often is described as the second leading cause of preventable death (tobacco use is the first) in the United States. However, in addition to difficulties faced by patients, providers have their own struggles in assisting patients with weight loss (Box 37-2).

Box 37-2. Common Pitfalls to Obesity Management

- Not regularly identifying obesity as a health problem
- Neglecting patient time and cost concerns in counseling efforts
- Not addressing need for family involvement in weight loss efforts
- Not recognizing environmental barriers to healthy lifestyles
- Not incorporating cultural expectations of ideal weight into weight loss goals
- Allowing the health consequences of obesity to overwhelm clinical encounters, leaving little time for weight reduction counseling
- Lacking the skills to counsel patients on weight loss

IDENTIFYING OBESITY AS A HEALTH ISSUE

Although overweight and obesity can be identified through the BMI calculation, practitioners have historically identified, documented, and counseled only a fraction of patients whose BMI classified them as obese.[43,44] Without identification of obesity, management strategies cannot be planned.

For health-care institutions that have adopted electronic health records, most automatically calculate BMI if height and weight are entered as vital signs. However, the challenge remains whether or not the treating health-care provider considers the abnormal number and works with the patient to manage excess weight. Approximately 69% of doctors report using electronic health records in their practice of medicine.[45]

BARRIERS TO WEIGHT LOSS COUNSELING

Health-care providers have identified barriers to weight loss counseling: insufficient time, disbelief that counseling will help, and lack of skills to provide counseling.[46,47] Although obesity often underlies many health problems faced by patients, the other acute and chronic medical problems generally become the focus of care. When faced with high blood glucose, clinicians usually choose to treat the diabetes and save the more complicated discussions of weight loss for later. Low-income and minority patients often have multiple medical and nonmedical issues limiting time for weight reduction counseling in routine clinical encounters. Until the 2011 announcement that Medicare would reimburse for primary care counseling

in obese beneficiaries, there was also no financial benefit to providers to offer support. Furthermore, many patients from these groups have not been as successful with weight loss as white participants in large (nonculturally tailored) weight loss trials.[48] Consequently, health-care provider expectations of success may be low, which further hinders clinician initiation of counseling. Despite brief intervention methods that have demonstrated success with weight loss,[46] providers continue to struggle with implementing counseling into their practices.

TIPPING THE SCALE IN FAVOR OF HEALTH

APPROACH TO WEIGHT CONTROL

Identify the Problem with Patients

Each patient encounter is an opportunity to address weight management. Obese and overweight adults with obesity -related comorbidities or cardiac risk factors and children who are overweight or obese should be targeted. Height, weight, and BMI should be recorded at every visit. For children, BMI should be plotted onto an age-specific BMI growth chart (see Box 37-1).[49] Cardiac risk factors and comorbidities related to obesity should be assessed. Elderly patients who are obese should be advised to lose weight. Weight reduction has similar effects in improving cardiovascular disease risk factors in older and younger adults.

The provider should communicate to the patient the specific BMI and the related diagnosis, actually using the term obesity, if applicable. Also, inform patients that obesity puts them at risk for related comorbidities and how it impacts their current health conditions (see Table 37-1).

Personalizing the message can be a useful tool. For example, patients may respond more to the message that weight puts them at risk for diabetes if they have family members who have suffered complications from diabetes. Patients' concerns about being overweight should be elicited as well. In all interactions, a nonjudgmental and supportive attitude is essential in effectively communicating about weight control.

Motivate the Patient (and Family) to Make Changes

Behavioral changes are difficult to achieve. If patients are not ready to make the necessary adjustments that losing weight requires, providers' counseling efforts can fall on deaf ears. The Prochaska and DiClemente stages–precontemplation, contemplation, action, and maintenance–can be used to assess patients' motivation for weight loss (see Chapter 12). A precontemplative patient is not ready to lose weight and may not recognize how his or her behavior contributes to the problem. The contemplative patient is considering but not committed to change. In the precontemplative and contemplation phases, providers should focus on increasing readiness to lose weight. Readiness can be explored further by assessing patients' sense of importance of a specific behavior change and confidence in their ability to make the change. In the action phase, a patient is either losing weight or is ready to. This is the ideal time to target weight loss interventions. The maintenance patient has lost weight and is trying to keep it off. With children, the entire family must be ready for change. Because children can gain weight quickly, frequent visits can be helpful in reassessing family motivation.

Set Realistic Goals with Patients

Patients often have unrealistic weight loss goals. In most weight loss interventions, participants rarely lose and maintain more than 10% of their body weight, although many patients want to lose much more of their current body weight.[50] Traditional teaching dictates that providers should help patients set realistic and attainable goals to minimize disappointment. This has been called into question, with recent evidence suggesting that patients may lose more weight if they set higher goals.[51,52] Regardless, providers should work collaboratively with patients to set goals that are attainable in a reasonable amount of time. Decreasing body weight by 5–10% over 6 months generally can be obtained by a weight loss of 1–2 pounds per week depending on a patient's BMI. A change in BMI that moves patients from the obese to overweight category is a success. In growing children, stabilizing weight gain is a desirable and attainable goal. Weight loss should only be attempted in adolescents who have completed their sexual maturity and bone growth.

Goals should not be limited to weight loss. For some patients preventing further weight gain and maintaining a lower weight for the long term are appropriate goals.[53] Goals not involving weight also can serve as motivating influences. Some examples of realistic and attainable non–weight loss goals include fitting into a certain clothing size, taking a regular walk with family after dinner, adding daily fresh fruits or vegetables, or simply feeling better about oneself.

Counsel on Improving Diet

Any successful weight loss effort incorporates changes in diet. Despite lack of formal training and time constraints, providers can and should play an active role in this area.

Elicit Useful, Accurate Information

A food diary–a detailed record of everything eaten during the day–provides the most accurate information about what the patient is eating, although they are difficult to complete. Alternatively, the patient can be asked to name everything eaten in the past 24 hours, including beverages and snacks. Other useful information includes how often the patient eats out, at what types of restaurants (making sure to specifically ask about fast food), what beverages are typically consumed, and how meals are prepared (e.g., fried, baked, broiled). The information gleaned can

be used to provide personalized messages about healthier eating. For example, a teenager eating fast food several times a week can be counseled to reduce intake by replacing a value meal with a kid's meal and replacing high-calorie foods such as French fries and a milk shake with a side salad and water. Keeping a detailed food diary itself has also been associated with weight loss.

Portion Size

Most people eat too much as an individual serving. Unfortunately, US restaurants, which often serve two to three times as much as the appropriate serving, fuel this. A simple teaching plate diagram or the MyPlate logo (ChooseMyPlate.gov) can help educate patients about portions, instructing patients that for lunch and dinner half of the plate should be composed of fruits and vegetables, a quarter meat or other source of protein, and a quarter carbohydrate (Figure 37-2). This results in larger servings of fruits and vegetables and decreases in meat and starches. Appropriate serving sizes also can be equated with everyday objects. For example, a serving of meat should be roughly the size of a deck of cards; a serving of rice, pasta, or potato, the size of a half a baseball; and a baked potato, the size of a fist.[54]

Fad Diets

It is important to counsel patients appropriately about fad diets. The data suggest that low-carbohydrate diets cause people to lose more weight in the short term, but that at 1 year the amount of weight lost is similar to more conventional low-fat diets.[55] These diets are difficult to maintain. For patients who are very interested in trying a fad diet, the initial weight loss can serve as a kick-start, but patients must realize that better long-term eating habits will be necessary to keep weight off.

A Balanced, Healthful Diet

When counseling patients about diet options, healthier approaches that recommend a well-balanced eating plan of fresh fruits and vegetables, whole grains, low-fat dairy, and lean protein are best. The DASH (Dietary Approaches to Stop Hypertension) eating plan, based on research studies sponsored by the NHLBI, is an example of such an approach.

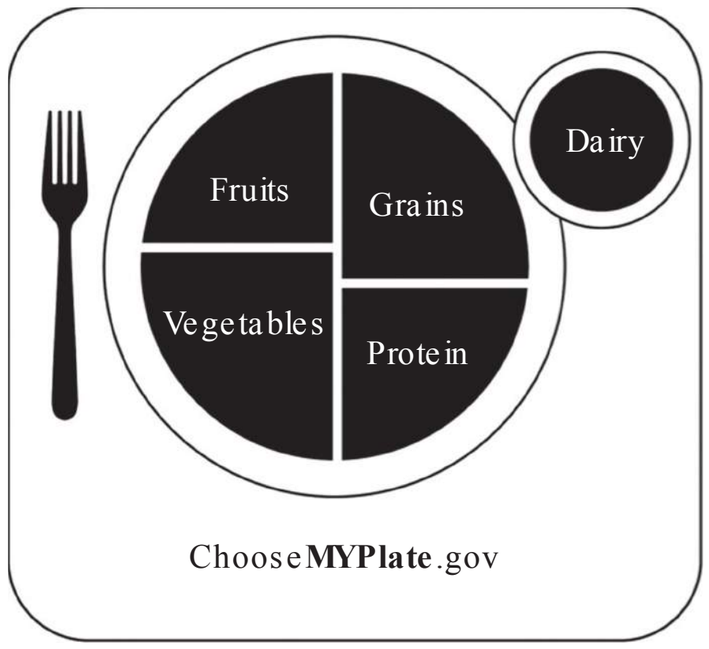


Figure 37-2. MyPlate diagram. Food portions: What your plate should look like. MyPlate illustrates the five food groups that are the building blocks for a healthy diet. (Source: U.S. Department of Agriculture. Center for Nutrition Policy and Promotion. http://www.choosemyplate.gov/.)

Counting Calories

To lose weight, calories expended must exceed calories taken in. To lose 1 pound per week, one must have a deficit of 500 kcal/day. Often, this can be achieved by a diet of 1,000–1,200 kcal/day for women and 1,200–1,600 kcal/day for men.[56] Selecting whole grain products for carbohydrates, reducing soda and juice, moderating alcohol, and increasing water consumption are other steps that can help.

Skipping Meals

Patterns of food consumption may also influence rates of obesity. While patients who stringently fast and decrease their caloric intake as a method of weight control do indeed lose weight, skipping meals, especially breakfast, results in binging and metabolic changes that may increase fat deposition. People who skip breakfast have higher rates of obesity and eating breakfast is associated with successful weight loss maintenance. Breakfast skippers tend to eat excessively at the next meal, or succumb to snacking on high-calorie food to stave off hunger. Late night snacking may also lead to increased weight gain. Several studies also suggest that people tend to add more body fat when they eat fewer, larger meals than when they eat the same number of calories in smaller, more frequent meals.

Sleep hygiene

Multiple studies of sleep duration and weight gain, particularly in children, have reached the same conclusion–short sleep duration is associated with subsequent weight gain. Indeed, the Institute of Medicine recently recommended the promotion of age-appropriate sleep durations as a primary goal in the prevention of childhood obesity.

Patient's Long-Term Commitment

Commitment to change is essential, but need not occur overnight. In fact, gradual change is more likely to be sustainable. Keeping track of dietary intake increases awareness of what a person is eating and problem in eating patterns. Support is indispensable. Congratulate and reward patients' successes, comfort them when they have setbacks, and encourage them to keep trying.

COUNSEL ON PHYSICAL ACTIVITY

Although exercise alone is not enough to cause substantial weight loss, in some studies it has resulted in greater weight loss than diet alone. Additionally, regular physical activity is essential in prevention of weight regain. The benefits of exercise include increased cardiovascular fitness, lower blood pressure, increased lean body mass, boosts in energy, stress relief, and improved sleep. Joining

a gym or jumping right into a rigorous exercise program is unappealing and unwise for most seasoned couch potatoes. It is important to start slowly. Using everyday activities to increase exercise is an easy first step: taking the stairs instead of the elevator, getting off the bus a stop early and walking the extra blocks, or exercising while watching television. Without costly memberships or a significant time commitment, these steps can significantly increase physical activity when done consistently.

Exercise can be incorporated into family life, both increasing health and fostering bonding. Families can take walks after dinner or take classes together. Children should be encouraged to participate in after-school programs or extracurricular activities in which they can be physically active. Parents can serve as role models for good health behaviors by being physically active.

ADDITIONAL RESOURCES TO AID DIET COUNSELING

Providers can use many resources to aid in diet counseling efforts. Dietitians educate patients in healthy eating behaviors and can provide detailed patient-specific advice. Unfortunately, depending on regional variations and insurance coverage, patients may have difficulty accessing these services. Books and Web-based information are more widely accessible (see Resources).

Smart phone apps are an increasingly used resources. Apps can allow a user to easily count and track caloric intake, find healthy eating options based on GPS locations, and easily access healthy recipes.

A review of commercial weight loss programs found little data to support their use based on efficacy and cost-effectiveness.[57] The sole exception was Weight Watchers, which resulted in a modest weight reduction, but more weight loss at 2 years than a self-help group that received minimal structured education.[58]

PHARMACOTHERAPY FOR WEIGHT LOSS

Both patients and health-care providers alike seek the "miracle weight loss pill." Unfortunately, none of the past prescription weight loss medications (phentermine and orlistat) has proven to be miraculous in its effects. New FDA-approved medications (lorcaserin and phentermine/topiramate) show some promise,[59] but more time and use will be needed to fully appreciate efficacy and side effects. Although FDA-approved weight loss medications are worth considering in the management of obesity, their cost, which ranges from $60 to $200 per month can be prohibitive for resource-poor individuals.

Who should receive weight loss medications? Guidelines have been established to aid practitioners with the appropriate use of weight loss medications.[60] Information

Table 37-2. Weight Loss Medications

Medication	Mechanism	Side Effects	Use in Children	Dosing	Initial Effect	≈ Cost
Phentermine (Adipex)	Sympathomimetic amine: appetite suppression	Dry mouth, insomnia, transient increase in blood pressure and heart rate	Adolescents 17 years and older	30 mg daily	7.9 kg weight loss > placebo	$60/month
Orlistat (Xenical)	Lipase inhibitor: decreased fat absorption	GI: flatus, incontinence, bloating Impaired vitamin absorption	Ages 12 and older	120 mg TID with meals	3.4 kg weight loss > placebo, 6.9% weight loss at 4 years	$120/month
Lorcaserin (Belviq)	Serotonin-2C receptor agonist: appetite suppression	Headaches, dizziness, dry mouth	Not approved for children	10 mg BID	5% weight loss, 3% > placebo	$150/month
Phentermine/ Topiramate (Qsymia)	Sympathomimetic amine: appetite suppression Unclear mechanism	Paraesthesia, dizziness, insomnia, dry mouth	Not approved for children	7.5/46 mg daily 15/92 mg daily	8% weight loss 10% weight loss	$160/month
Naltraxone SR/ Buproprion SR (Contrave)	Opiod antagonist: Unclear mechanism	Dopamine reuptake inhibitor: appetite suppression– Nausea, dizziness, headache, dry mouth, increase in blood pressure, constipation	Not approved for children	6/180 mg BID	10% weight loss	$200/month

Source: Adapted from Bray and Ryan,[59] Gadde et al,[72] Fidler et al,[73] Ornellas et al[74]

about medications currently on the market is included in Table 37-2. Weight loss medications always should be given in addition to behavioral therapy (diet and exercise). Their use can be considered in patients with a BMI of 27 and comorbidities (e.g., hypertension, diabetes, hyperlipidemia, obstructive sleep apnea), or a BMI ≥30.

In addition to FDA-approved medications designed specifically for weight loss, there are medications used for other chronic conditions that have sometimes beneficial side effect of weight loss. These should be considered in patients who have obesity and another relevant condition: metformin for patients with diabetes, topiramate for patients with migraines/chronic headaches, and bupropion for patients with depression.

BARIATRIC SURGERY FOR WEIGHT LOSS

Bariatric surgery is the most invasive as well as the most effective method available to assist patients with weight loss. In general, the goal of bariatric surgery is to decrease the size of the stomach to limit the intake of food and decrease the absorption of foods eaten. There are many types of bariatric procedures. The two most commonly used by US surgeons are the Roux-en-Y gastric bypass and the sleeve gastrectomy.

CANDIDATES FOR BARIATRIC SURGERY

Patients can lose between 20 and 40 kg through bariatric surgery.[61] Health outcomes for patients who undergo bariatric surgery have been well established. Improvements or resolution of high blood pressure, diabetes, high cholesterol, sleep apnea, and musculoskeletal symptoms are expected after successful weight loss from bariatric procedures.[62]

Regarding children, several pediatric hospitals around the country began performing bariatric surgery in morbidly obese adolescents who have reached skeletal maturity and who have comorbid conditions that would benefit from sustained weight loss. It is generally recommended that adolescents considering bariatric surgery seek care in a well-established pediatric obesity center.[63]

The average cost of bariatric surgery is $15,000–$25,000 depending on the procedure (www.obesity coverage.com). Some insurance providers, including Medicaid and Medicare, cover the surgery if it is deemed a medical necessity and the NIH criteria outlined in Box 37-3 are met; however, for low-income individuals without insurance who are often medically eligible for the procedure, the cost of surgery can be prohibitive. This barrier to access creates a new area of health inequity in vulnerable populations.[64]

POSTOPERATIVE COMPLICATIONS AND CARE

There are several common post–bariatric surgery complications. The most common complications are iron and B_{12} deficiencies. Consequently, providers should follow a patient's CBC and iron profile every 3 months for a year and then yearly and should provide appropriate supplementation. Osteoporosis can occur in post–bariatric surgical patients. Its cause is unclear, although it may involve the impaired absorption of calcium and vitamin D. Primary care providers should consider evaluating patients for osteoporosis and treating them with calcium and vitamin D when necessary.[66] Gallstone formation (cholelithiasis) is a common occurrence after major weight loss of any kind; therefore, it is particularly common in patients who undergo bariatric surgery. In addition to close medical monitoring, patients should be involved in a postoperative program to assist with weight loss maintenance. For many patients, the changes in diet and eating patterns (small frequent meals) can be quite different from their usual eating styles or those of their families.

Box 37-3. Who Is a Candidate for Bariatric Surgery?

- Have had obesity for at least 5 years
- Have a BMI >40 kg/m^2 or >35 kg/m^2 with two comorbid conditions that would benefit from weight loss (e.g., hypertension, diabetes, hyperlipidemia, steatohepatitis, coronary artery disease, obstructive sleep apnea)
- Have failed medically supervised nonsurgical methods of weight loss
- Have no significant psychopathology

From Collazo-Clavell ML. Safe and effective management of the obese patient. Mayo Clin Proc 1999;74:1255-1259.[65]

MULTIDISCIPLINARY AND INTERDISCIPLINARY APPROACHES TO WEIGHT CONTROL

Esmeralda is referred for psychiatric evaluation and her family is assigned a case manager. A dietitian and physical therapist help design plans for the family. Esmeralda receives an excuse for not taking swimming at school because of her refusal to wear a bathing suit in front of other students. However, she agrees to take part in other physical activities that do not require exposing her body.

Social, biological, and psychological factors interact in the development of obesity; therefore, a team approach may be necessary to cope with this multifactorial problem. For some patients with longstanding relationships with primary care providers, evaluating the contributing factors and giving suggestions to alter those factors may be all that is required to affect healthy changes. However, for other patients who may not receive regular medical care

or have complicated medical and social issues, multidisciplinary or interdisciplinary treatment can be an effective way to manage weight issues.

In the era of the Chronic Care Model and patient-centered medical care, team approaches to care that include the patient have improved outcomes for a variety of medical conditions including several related to excess weight.[67,68] The necessary components of a weight loss treatment program should address social (financial resources, food security, neighborhood safety), biological (comorbid conditions related to obesity), behavioral (readiness for change, confidence, self-efficacy), and psychological (depression, anxiety) factors. Therefore, clinic redesign with a multidisciplinary team might include clinicians (physicians, nurses, dietitians, behavioral therapists, physical therapists) and nonclinicians (social workers, health educators, behavioral therapists, community partners). For a variety of reasons–cost, transportation, time–the more team members who can connect with a patient during a single visit, the more likely multiple aspects of care will be appropriately addressed. Multidisciplinary clinics or interdisciplinary group classes and visits may be useful in this regard (see Chapters 16 and 19).

PUBLIC HEALTH AND POLICY APPROACHES TO WEIGHT CONTROL

Although individual approaches to weight loss serve to improve a single person's health, larger public health approaches can effect change on a population level. Many health-care providers are motivated to advocate for change outside of the clinical setting because strong recommendations for healthy living are often overwhelmed by the obesogenic environments in which patients live. Public health and health policy initiatives in a variety of settings can promote and support healthy lifestyle behaviors in large numbers of people regardless of income, educational status, and ethnicity.

Community-based approaches include considering fitness and physical activity in the design of cities, neighborhoods, and buildings (the built environment): creating reliable and well-integrated mass transportation systems; equipping office and commercial space with well-lit, easily accessible stairs; or designing neighborhoods with sidewalks and trails for biking and walking. In already established communities, local governments can make funding for recreational centers, green space, bike lanes, and safe playgrounds a priority. Employers can provide on-site exercise facilities or incentives for their employees to join fitness centers or take classes promoting healthy behaviors. The education of key community figures, such as religious leaders, medial personalities, and high-profile public personalities (e.g., First Lady Michelle Obama) can serve to disseminate health messages in an efficient and effective manner. Furthermore, partnerships among academic medical centers, community organizations, and local governments can facilitate the creation, implementation, and evaluation of the impact of public health efforts targeting obesity.

Schools are particularly important places for healthy behavior initiatives. In 2012, the United States Department of Agriculture (USDA) released new school lunch standards that require an increase in fruits and vegetables, whole grains, and a reduction in sodium in the food they serve. These changes touch millions of children who rely on schools for most of their weekly food consumption. In 2013, the USDA released vending machine standards that promote healthier snack options on US school campuses. In addition to these food policies, schools are an excellent location to teach children about physical activity, healthy eating, and healthy food preparation. Educational initiatives such as age-appropriate and culturally sensitive nutrition classes should be required in schools. Teachers, support staff, and parents should be educated on the benefits of proper nutrition and physical activity–even in short bursts. Reinstating recess and physical education classes in schools and encouraging participation in extracurricular activities that involve sustained movement–including nontraditional ones such as Zumba, line-dancing, or traditional cultural dancing–can reinforce the importance of physical activity. Lastly, health promotion messages can take the place of fast food and soft drink advertising near school grounds.

Federal policy initiatives such as those enacted by the USDA can have a significant impact on obesity. Likewise, within the Affordable Care Act is a provision that chain restaurants with 20 or more locations must post calorie content on their menu boards in letters of comparable size as the price. Once this policy is fully implemented, health-care providers will be able to coach patients on appropriate calorie counts for their meals. Other more broadly focused policy considerations include the development and use of simplified nutritional rating scales (1, 2, or 3 stars based on nutritional profile) that would be used by grocery stores to simplify the process selecting the healthiest products for purchase[69] and taxation of sugar or sugar-sweetened beverages.[70]

Voluntary industry policies can also reach millions. In 2012, Walt Disney Co. agreed to limit junk food advertising on Disney television, radio, and online programs targeting children younger than 12 years. Fast food and soft drink advertising could be prohibited during all children's television programs. Taxes could be levied on fast food and other unhealthy snacks, whereas fruits and vegetables and healthy food options could be subsidized. Also, the food and beverage industry could be required to provide reasonable portion sizes in restaurants.[71] Government subsidies for growing corn (corn syrup) and sugar could be eliminated or transferred to support the growth of fruits and vegetables.

These nonclinical, wide-scale approaches to the promotion of healthy eating and physical activity have the potential to enhance and support the targeted work done by clinicians with patients.

CONCLUSION

Over one half of US adults and nearly one-third of children are overweight or obese. Weight loss can be an extremely difficult process. Time commitments, the cost of healthy foods, limited opportunities for physical activity, and lack of awareness of the negative effects of obesity can all be barriers to weight loss. Health-care providers have an opportunity to assist patients with this important health issue through care of their individual patients and support of community and public health initiatives. Together with health-care providers and patients, large-scale efforts will help reverse the trend of ever-increasing rates of obesity.

- Identify obesity in patients.
- Calculate BMI.
- Explicitly address the issue of obesity.
- Motivate patients to lose weight.
- Consider cultural norms and time constraints specific to individual patients and their families.
- Set realistic goals.
- Counsel on diet and physical activity modifications.

Action Plan for Weight Loss

Pre-Action Plan

- Provide an accurate weight assessment.
- Assess readiness for change.
  - —Precontemplators:
    - Counsel weight maintenance.
    - Review the health consequences of obesity.
    - Assess confidence in ability to change and importance of need to do so.
  - —Contemplators
    - Tip the balance: strengthen reasons for weight loss.
    - Assess confidence and importance.

Action Phase: Make the Action Plan

- Have patient identify his or her reasons for weight loss.
- Brainstorm on achievable goals: Walk 10 extra minutes a day three times a week; drink diet soda instead of regular soda.
- Identify desirable, nonfood rewards as motivation to achieve goals.
- Outline a dietary plan: "I will eat breakfast every day." "I will restrict eating out to once weekly."
- Outline a physical activity plan: "I will park at the far end of the parking lot at the grocery store," "I will play soccer with my children on Saturday mornings."
- Review additional supportive resources (nutritionist referral, weight loss medications, family counseling, etc.).
- Brainstorm on ways for the patient to keep weight off once it has been lost.

DISCUSSION QUESTIONS

1. Discuss three of the many factors that make it difficult for you or someone you know to lose weight. How might you overcome those difficulties?
2. Describe the steps a health-care provider should take to help a patient lose weight.
3. Esmeralda's mother has been your patient for 5 years. She happily reports to you that her both daughters have been losing weight over the last year. Your medical record shows that she has gained 5 pounds in the last year and her diabetes control has worsened ($HbgA_{1C}$ has risen from 7.5 to 9.0). Describe how you might approach your patient's weight gain.

RESOURCES

Weight-Control Information Network: A Web site produced by NIH and the National Heart, Lung, Blood Institute to assist patients and providers with weight loss. http://win.niddk.nih.gov.

A Web site with information for African-American women regarding BMI, physical activity, nutrition, and weight loss goals. http://www.blackwomenshealth.com.

A Web site by the USDA that allows individuals to learn how to balance their plate, to eat on a budget, and know the calories of common foods. www.ChooseMyPlate.gov.

An electronic guide to recent, high-quality resources and information tools for overweight in children and adolescents. http://www.mchlibrary.info/knowledgepaths.

BMI calculator. http://www.cdc.gov/nccdphp/dnpa/bmi/calc-bmi.htm#English.

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Chapter 38

Chronic Pain Management in Vulnerable Populations

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Objectives

- Describe the disproportionate burden of chronic pain in medically vulnerable populations.
- Describe comorbidities that can present challenges in the management of chronic pain.
- Describe a general approach to the evaluation and management of chronic pain.
- Review common treatments, with a special focus on the role of opioids in the management of chronic pain.
- Suggest practical tools to improve the provision and documentation of safe and effective care for chronic pain.

INTRODUCTION

Chronic pain usually serves little or no physiologic role and, in contrast to acute pain, it is perhaps best viewed as a disease state, not a symptom. An estimated 100 million American adults are afflicted with chronic pain, which is more than the number affected by heart disease, cancer, and diabetes combined.[1] Globally, 10% of the world's population or 60 million people suffer with chronic pain, and the World Health Organization (WHO) estimates that 1 in 10 adults are newly diagnosed with chronic pain each year.[2] In Europe, one in five adults report chronic pain.[3] Chronic pain affects both physical and mental health and leads people to rate their health as poor[4]; hence, its social and economic costs are considerable. Pain-related problems, particularly chronic pain management, are among the most challenging clinical problems confronted by clinicians.[5] This chapter reviews general principles of chronic pain management, emphasizing special circumstances confronted by clinicians caring for medically vulnerable populations. The aim is for clinicians to feel empowered to provide empathic and comprehensive evidence-based care for their patients.

DISPROPORTIONATE BURDEN OF PAIN IN VULNERABLE POPULATIONS

> JP has a history of an alcohol use disorder, major depression, and chronic low back pain following a workplace injury. He is unemployed due to his pain and is at risk of losing his housing due to lack of income. He has no history of fevers, weight loss, cancer, or other "red flag" symptoms. He fears this pain will only get worse and he will eventually need a wheelchair. He pleads for help because his pain is "absolutely out of control."

The burden of moderate to severe chronic pain is highest among the poor, the uninsured, and those belonging to ethnic minorities.[6] Poor individuals are subject to hazardous and physically demanding work or living conditions that lead to physical injury. Chronic pain itself creates economic or social disparities by causing disability or loss of health insurance[1] and treatments that could reduce or manage symptoms are often unattainable. Pain sufferers who are poor or uninsured may have difficulty navigating the health-care system to obtain proper treatment.

Further, mental health conditions such as depression and anxiety are more prevalent among underserved medical populations and may impede appropriate management of pain.[6] Finally, personal interaction styles, discordant cultural beliefs, and stereotypes held by both clinicians and patients may undermine communication leading to effective pain treatment.

Internationally, it is also true there is a disproportionate burden of persistent pain among the disadvantaged and people of lower socioeconomic status.[7] The inequity of pain mirrors the inequality in disease. For example, the WHO estimates that 70% of the 20 million new cancer cases expected to occur by 2020 will afflict persons in the developing world. There is also a significant shortage of treatments for chronic pain, both pharmacologic and nonpharmacologic, causing wide-spread untreated pain.[8]

CLASSIFICATIONS OF CHRONIC PAIN

> JP complains his pain is constant and localizes to both sides of his low back. It is a "throbbing and tight pain" with occasional radiation down the leg, but no weakness, numbness, or bowel or bladder symptoms. The physical exam is notable for his moving slowly and grunting when he changes positions, paraspinal tenderness to palpation and a normal neurologic exam.

The International Association for the Study of Pain (IASP) defines pain as a combined sensory, emotional, and cognitive phenomenon: it is "an unpleasant sensory and emotional experience that we primarily associate with tissue damage or describe in terms of such damage, or both." Pain becomes chronic when it persists beyond the time normally associated with healing from an acute or subacute injury (usually 4 to 12 weeks). It may be constant, intermittent, or related to physical activity. Most pain (acute or chronic) can be further classified as inflammatory or nociceptive (i.e., arthritis), neuropathic (i.e., postherpetic neuralgia), or idiopathic (i.e., fibromyalgia). These classifications are based on experimental evidence that different mechanisms underlie the cause of pain in each case. Chronic pain sufferers often experience several types of pain. For example, chronic low back pain due to osteoarthritis is normally classified as inflammatory, but there is often associated irritation of the nerves (neuropathic), and the sensory activation in the periphery may also be associated with sensitization of the central nervous system (i.e., neuroplastic changes).[9]

Pain medicine has been shaped by the seminal observation in 1987 by Gordon Waddell of the biopsychosocial model in low back pain. This model established that clinicians need to understand pain not only from the biomedical perspective but also from the ways that pain is modulated by the patient's perception and his or her social context. Pain thus includes three distinct components: a sensory-discriminatory component (e.g., location, intensity, quality), a motivational-affective component (e.g., depression, anxiety), and a cognitive-evaluative component (e.g., thoughts concerning the cause and significance of the pain).[10] This framework requires understanding the characteristics of the pain, the psychological responses to pain, how and why the pain has changed a person's life, and the implications for recovery.

CHALLENGES IN DIAGNOSIS OF CHRONIC PAIN

> JP describes his pain as "unbearable." He is now unable to take care of his grandchildren. He is depressed, sleeps poorly due to pain, and is less interested in activities that he enjoys. He has been drinking more alcohol to "forget about his pain" and fall asleep. He drinks four shots of liquor daily and has been to rehabilitation programs in the past.

Clinicians must rely primarily on patient report of the presence of pain and its severity. This is not an easy task, Virginia Woolf famously noted that when confronted with pain, "language runs dry." Although at once universal and subjective, pain varies in its expression both among and within individuals.[7,11] The response to pain may be histrionic or stoic, panicked or accepting, help seeking or highly skeptical of help.[12] Assessing and classifying it can be challenging, but is a necessary step in selecting the right treatment. Often there are multiple potential causes of physical or emotional pain. Patients may have trouble communicating their subjective symptoms or may exaggerate the extent of their symptoms. Hence, a holistic understanding of the patient is often as important as defining pain according to traditional classifications. It can be helpful to have patients maintain a pain diary (i.e., record when pain occurs, how it feels, and response to interventions) to aid in the diagnosis. In addition, it is important to explain that there is usually not a "quick fix" for chronic pain. The best treatments are multimodal, involving a combination of medication, physical activity, rehabilitation, learning coping skills, mental health care, and complementary treatments. A variety of therapies need to be tested to achieve successful pain control.

Many providers express frustration with treating chronic pain patients. Lack of time, poor treatment resources, and a lack of adequate training all contribute to this sentiment.[11] In turn, patients may feel as though their provider does not believe them, or finds them burdensome.[12] Importantly, chronic pain patients are most satisfied if their provider takes the time to listen to their complaints, understand his or her level of suffering, and practices shared decision making.[13,14] A strong patient–provider relationship is also associated with better

adherence to the treatment plan.[15] Shared goal setting of mitigation rather than cure helps the clinician feel more confident and satisfied in treating chronic pain patients.

CHRONIC PAIN AND MENTAL HEALTH

In many cultures worldwide, it has been observed that chronic pain is highly comorbid with psychiatric disorders, particularly mood disorders. Chronic pain is more common in depressed patients, and patients with both disorders have pain complaints that are more frequent, more intense, and more intractable. An estimated 10–30% of chronic pain patients have depression, compared to 6.7% of the general population.[16] Depression and pain exacerbate one another, such that increased pain causes worse depression and vice versa.[17] Chronic pain patients also suffer disproportionately from anxiety disorders and posttraumatic stress disorder.[9]

In addition to the burden of mental illness, chronic pain patients, particularly those living in poverty, suffer hardships that make day-to-day living extremely difficult. Pain can be modulated by a variety of external factors, including the effect of the pain on current life activities; learned behaviors and beliefs from family, cultural, and socioeconomic background; and the meaning of the event that caused the pain. Clinicians and care teams have an instrumental role in helping alleviate suffering by connecting patients to mental health care; assisting with basic needs such as food, housing, and transportation; and empowering patients to establish control over their illness.

CHRONIC PAIN AND SUBSTANCE USE DISORDERS

Chronic pain is common among patients with substance use disorders.[14,18] For example, among patients with an opioid use disorder receiving methadone maintenance or buprenorphine, 60% and 35% of patients report chronic pain, respectively.[19,20] Self-reported pain is also extremely common among persons in substance use treatment with a history of prescription opioid abuse. Chronic pain also affects patients with alcohol and stimulant use disorders.

There are various explanations for this association. Injuries occur more commonly in people who are impaired by alcohol and drugs, and in fact, half of trauma patients are intoxicated at the time of injury.[21] Certain chronic pain conditions affect substance users disproportionately, for example, chronic pancreatitis in alcohol use disorders. Pain itself may be a symptom of the addictive disease, present during withdrawal and contributing to relapse.[22] Addicted patients may perceive that alcohol or drug helps cope with pain. The reality is that chronic pain and addiction often are synergistic, reinforcing dysfunction, sleep disturbance, and mental illness. Substance use disorders are highly associated with mental health disorders, which may cause or exacerbate pain. Finally, there is evidence that substance use alters the nervous system and affects pain perception. For example, chronic opioid abuse is associated with changes in the opioid receptor, which may increase pain sensitivity.[23] There is also similar dysregulation of the nucleus-accumbens-medial prefrontal cortex reward pathway in both addiction and chronic pain.[24] Given how common these conditions occur together, providers managing chronic pain must be prepared to screen and evaluate for substance use disorders among chronic pain patients.

- Pain is a subjective experience and treatment goals are rarely achieved without a trusting relationship between clinician and patient.
- A narrow focus on the patient's primary complaint may miss the big picture.
- Unrealistic expectations for symptom relief may interfere with setting and achieving realistic goals.
- The trial and error nature of pain treatment may cause patients and clinicians to give up on their goals prematurely.
- Mental health problems may impede progress in managing chronic pain.
- Social and medical taboos may limit the selective and appropriate use of opioids for intractable chronic pain.
- Prescribing opiates in large doses may be easier for clinicians than comprehensively managing pain, particularly in low-resource settings or with addicted patients.
- Limited specialty resources or referrals may impede successful symptom management.

GENERAL APPROACH TO THE DIAGNOSIS OF CHRONIC PAIN

The first steps for the clinician are to obtain a complete history of events that triggered the pain, ascertain the level of pain, how the pain interferes with the patient's daily functioning and quality of life, and review prior diagnostic evaluations and treatments. Explorations about the patient's beliefs about the pain, its causes, and prognosis are very likely to focus and improve treatment.

PAIN HISTORY

Patient history should include questions about onset, quality, duration, and ameliorating or exacerbating factors. The level of pain should be assessed to understand what the patient is experiencing and measure the effectiveness of treatment. The most common assessment tool asks the

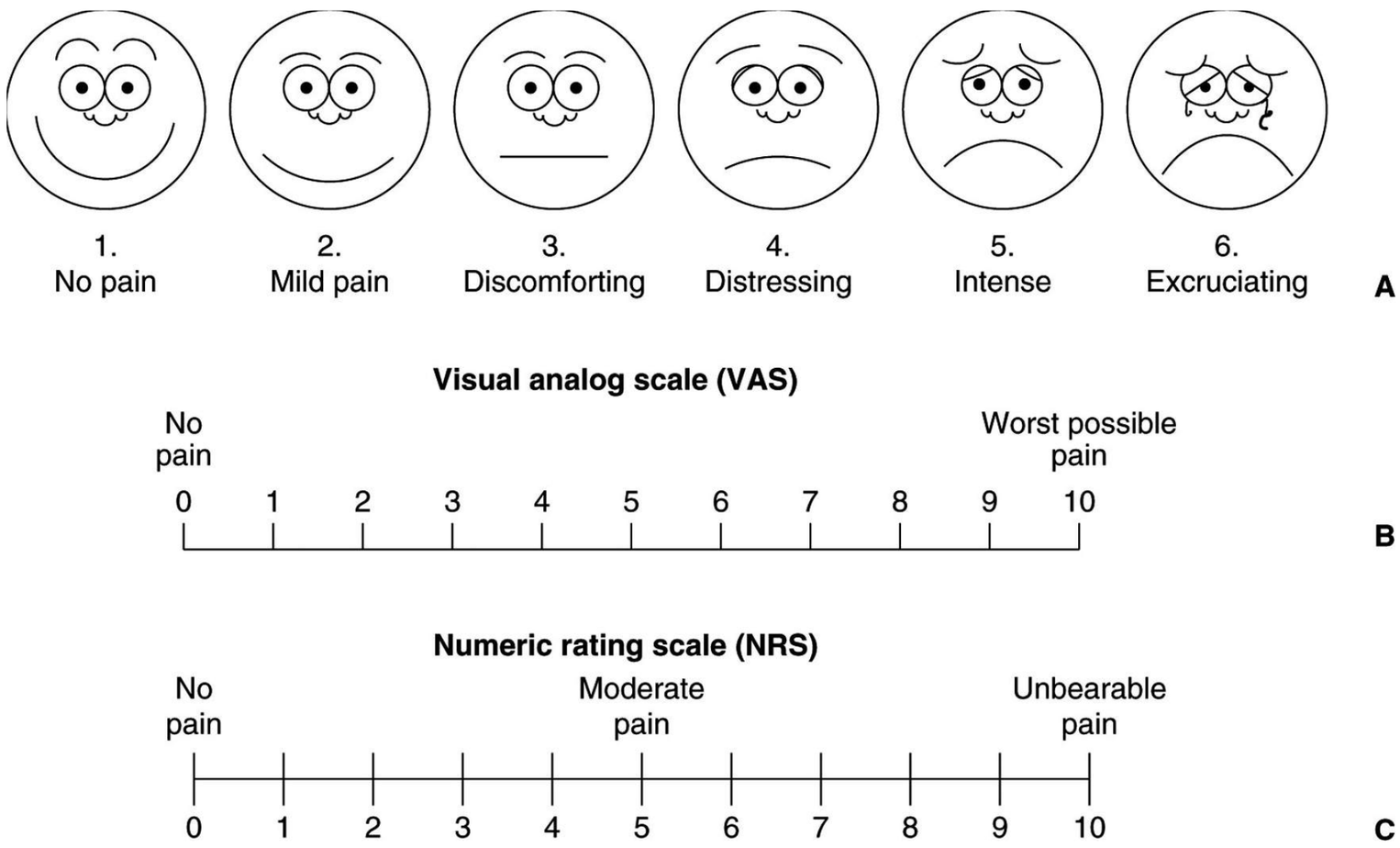


Figure 38-1. **A:** Faces pain scale. This scale presents pictures of six to eight different facial expressions depicting a range of emotions. (From Wong DL, Hockenberry-Eaton M, Wilson D, et al. Wong's Essentials of Pediatric Nursing, 6th ed. St. Louis: Mosby, 2001:1301.) **B:** Visual analog scale (VAS). The VAS is a validated approach to pain measurement. The most common VAS consists of a 10-cm line with one end labeled "no pain" and the other end labeled "worst pain imaginable." The patient marks the line at the point that best describes the pain intensity. The length of the line to the patient's mark is measured and recorded in millimeters. **C:** Numeric rating scale (NRS). The NRS is simple to use and is one of the most common approaches for quantifying pain. Patients indicate their pain intensity on a scale of 0 to 10, with 0 indicating no pain and 10 the worst pain imaginable. This scale is more sensitive to treatment-induced changes than the VRS. The NRS can be a helpful technique for clarifying the relationship between pain and activity, the effectiveness of pain treatments, and the pattern of the patient's pain. (Adapted from Jacox A, Carr DB, Payne R, et al. Management of Cancer Pain. Clinical Practice Guideline No. 9. AHCPR Publication No. 94-0592. Rockville, MD. Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service, March 1994. Available at http://www.hospicepatients.org/clinicalpracticeguidelines1994.html.)

patient to rate pain intensity on a numerical scale from 0 to 10 (or 0 to 100), in which 0 represents no pain and 10 represents unbearable pain. Pictorial or visual analog scales have also been used and are particularly useful for children, adults with low literacy, and elderly patients.[15] Both visual and numerical analog scales have been evaluated in international settings.[25,26] These scales are also helpful for clarifying the relationship between pain and activity, the effectiveness of pain treatments, and the pattern of the patient's pain (Figure 38-1). More elaborate and comprehensive pain assessment scales have been developed, for example, the McGill Pain Questionnaire. They take longer to administer and patients who are cognitively impaired or poorly educated may find these difficult to complete.

FUNCTIONAL ASSESSMENT

Common functional limitations caused by chronic pain include sleep disturbance, reduced mobility, sexual dysfunction, and decreased ability to perform well in social or work situations.[13] Failure to address functional limitations can lead to declining overall physical well-being, loss of important social and work relationships, and may trigger or exacerbate anxiety or depression. Evaluating work disability caused by pain and providing documentation may qualify a patient for entitlements that could improve his or her living situation. Advocacy for disability benefits, vocational retraining, and other community services are all part of comprehensive care.

Several validated scales can be used to assess and monitor chronic pain patients' functional status. Commonly used instruments include the Brief Pain Inventory (short and long versions), the Pain Disability Index, and the McGill Pain Inventory. The PEG is a short, three-item scale that assesses average Pain, interference with Enjoyment of life, and General activity, which is well suited for more rapid assessment in a primary care setting.[27]

MENTAL HEALTH ASSESSMENT

Treatment of comorbid mental health problems results in better clinical outcomes.[16] Therefore, screening for mental health disorders and any current or past substance use disorders is imperative. Validated questionnaires such as the Alcohol Use Disorders Identification Test and the Drug Abuse Screen Test can be helpful. Alternatively, there are several validated screening tools for primary care, including the single question drug and alcohol screeners (Box 38-1). In primary care settings, the single question alcohol question has been shown to be 81% sensitive and 79% specific

Box 38-1. Single Question Drug and Alcohol Screen Tests

- Alcohol screen question: "How many times in the past year have you had "X" or more drinks in a day?" (Where "X" is 5 for men and 4 for women and a response of 1 or more is considered positive.)
- Drug screen question: "How many times in the past year have you used an illegal drug or used a prescription medication for nonmedical reasons?"

for the detection of unhealthy alcohol use and the single question drug question has similarly been shown to be both sensitive and specific for detection of a drug use disorder.[28]

PAIN BELIEFS AND EXPECTATIONS

Exploration of the patient's beliefs about their pain may reveal particular cultural or personal factors that can be adjuncts or barriers to effective management. Pain may be an acceptable reason for disability or poor functioning, whereas depression or other mental health conditions are not. Many patients believe their pain indicates progressive damage to a part of the body and stop activities they believe could lead to further damage. This may exacerbate deconditioning and depression, thereby increasing pain and dysfunction. The expectation that the goal of treatment is complete elimination of pain may lead patients to seek treatments that could be useless or dangerous.

PHYSICAL EXAMINATION

A thorough physical examination is essential to the evaluation, and should include observations of the patient's appearance, behavior, and responses to physical maneuvers that might elicit or relieve pain. Specific attention should be given to the musculoskeletal and neurologic evaluation, as well as potential syndromes of referred pain. Nevertheless, objective findings on physical examination should not be relied on solely to confirm or disprove the patient's subjective complaint of pain.

GENERAL APPROACH TO MANAGEMENT OF CHRONIC PAIN

> JP has both an alcohol use disorder and major depression. He is interested in trying an antidepressant and returning to Alcoholics Anonymous to receive support. His provider reviews the nature of his pain explaining that it will neither be eliminated nor progress to complete inability to function. She expresses confidence that together they can manage his pain. His functional goal is to care for his grandchildren. Given his pain, sleep problems, and mood disturbance, a trial of gabapentin is prescribed and he is referred to physical therapy.

A history that elicits the patient's broader life experiences with pain may provide insight into what is needed for effective treatment. Pain associated with a psychologically traumatic event could improve with treatment for the emotional impact of that trauma or loss. Pain that interferes with work may respond to vocational retraining. Pain caused by an underlying chronic disease may improve through education or support groups that bolster coping skills. Simply explaining pain—the differences between acute pain and chronic pain; rudiments of how the nervous system works related to pain; the ability to manage pain using multiple types of approaches—has proven value.[29]

A mutually agreed upon treatment plan should address four important factors: the underlying causes of pain, how the pain is experienced, functional limitations, and realistic treatment goals. The treatment plan should allow both the clinician and patient to make priorities among treatment strategies and assess the success of treatments that are chosen.

FORMING A THERAPEUTIC ALLIANCE

A partnership with the patient (and his or her support people) that is marked by mutual trust and an understanding of the challenges that may lie ahead is the foundation of treatment. Effective pain management—often requiring extensive evaluations and treatments that never fully eliminate pain or completely restore physical function—is one such challenge in itself.

NONPHARMACOLOGIC THERAPIES FOR CHRONIC PAIN

The observations that pills alone are usually insufficient for complete pain control and functional recovery and can complicate treatment in their own right have increased interest in nonpharmacological pain treatments. For example, a meta-analysis of opioid therapy for chronic low back pain demonstrated only a small effect on pain and function, and many of the trials had high drop-out rates and excluded patients with any history of substance use.[30] Unfortunately, many classes of medication used for pain similarly show only moderate effects. Therefore, use of any single agent is unlikely to result in the elimination of pain. Instead, the patient and provider need to explore alternative options for treatment, some of which may not be pharmacologic. Table 38-1 provides a sample

Table 38-1. Approaches to Pain Management

Pharmacologic	Physical
• Anti-inflammatories (i.e., APAP, NSAIDs) • Anti-epileptics • Antidepressants (i.e., serotonin-norepineprine reuptake inhibitors [SNRIs], tricyclic antidepressants [TCAs]) • Anesthetics (i.e., analgesic balm, lidocaine patch) • Muscle relaxants (i.e., baclofen) • Topicals (i.e., diclofenac gel, lidocaine patch, capsaicin) • Opioid medications (i.e., morphine, oxycodone, buprenorphine) • Specialized pharmacologic treatments (i.e., medication-infusion pumps)	• Heat or ice • Recommendations for pacing daily activity • Stretching and strengthening exercises • Physical and/or occupational therapy • Physiatry or osteopathic consults • Bracing or orthotic evaluation • Massage therapy • Joint injections • Spine injections • Trigger point injections • Electrical stimulation (i.e., Transcutaneous Electrical Nerve Stimulation [TENS], spinal cord stimulator [SCS])
Complementary and Alternative Medicine	**Cognitive and Behavioral**
• Acupuncture and acupressure • Mindfulness-based stress reduction and meditation • Aromatherapy • Exercise classes (i.e., yoga, Tai-Chi) • Anti-inflammatory diets and herbs • Supplements (i.e., glucosamine chondroitin, S-adenosylmethinone [SAM-e]) • Breathing exercises • Guided imagery • Prayer • Medical marijuana	• Self-care models • Pain groups • Individual therapy • Cognitive and behavioral therapy (CBT) • Coping skills training • Visualization, deep breathing, meditation, relaxation • Biofeedback • Sleep hygiene • Apps and computer-based CBT • "Explain pain" • Gardening, being outdoors, listening to music, spending time with friends and family, art therapy, etc.

framework for the different modalities of chronic pain treatment, demonstrating a wide range of possibilities to be discussed with patients.

Many nonpharmacologic treatments may have an impact on the outside factors—the social, psychological, and spiritual—that contribute to a person's experience of pain. The level of medical evidence for many of these alternative treatments is limited, but countless patients and pain specialists advocate for a multimodal approach. Patients often seek complementary therapies either before or concurrently with conventional medical treatments,[17] and eliciting information about these therapies and incorporating them into their treatment plan when appropriate can strengthen the therapeutic alliance as well as protect patients from potentially harmful side effects.

PHARMACOTHERAPY FOR CHRONIC PAIN

Guidelines for the management of chronic non–cancer pain recommend directing the pharmacologic treatment to address the causes, character, and severity of the pain. In general, mild pain is best treated with analgesics such as acetaminophen or a nonsteroidal anti-inflammatory drug (NSAID), with or without adjuvant analgesics. Opioids are reserved for more severe pain, or when there are contraindications to less potent medications. In clinical practice, acetaminophen or NSAIDs are more likely to be effective first- or second-line agents for nociceptive aspects of the pain, whereas adjuvant analgesics such as anticonvulsants and antidepressants are more likely to be effective first- or second-line treatments for neuropathic pain. Opioids are effective for both nociceptive and neuropathic pain, but because of their side effects and potential for diversion and abuse, usually are reserved for moderate to severe pain and pain that is unresponsive to other therapies. In practice, combinations of these agents typically are used together and multiple empiric trials often are required to find the best treatment.

Adjuvant Analgesics

Adjuvant analgesics include muscle relaxants, antidepressants, tricyclic antidepressants, anticonvulsants, and alternative medications such as glucosamine sulfate, topical analgesics, and intra-articular steroids. Muscle relaxants (e.g., baclofen, cyclobenzaprine, and others) are used primarily as adjuvant therapy for musculoskeletal pain, especially back pain and muscle spasm of the neck and shoulders. The efficacy of these agents usually is modest, and they can be sedating or habit forming.[31] For chronic osteoarthritis pain of the knee and hip, glucosamine sulfate may be effective for some patients, with potentially lower risk of side effects than NSAIDs, but systematic reviews have not shown strong efficacy.[32] Systemic corticosteroids can successfully treat pain resulting from some inflammatory disorders and cancer-related syndromes, but their use for chronic pain usually is limited by the risk of serious side effects. Intra-articular glucocorticoid injections with or without hyaluronic acid also can be offered for arthritis pain.[33] For inflammatory arthritis, potent disease-modifying therapies are now available, and early referral for treatment may reduce pain and improve other disease-related outcomes.[34] Tricyclic antidepressants and anticonvulsants frequently are used for neuropathic pain.[35] The analgesic effect of tricyclic antidepressants is independent of their antidepressant effect, although their antidepressant effect may be helpful in patients with comorbid depression. Antidepressants acting on noradrenergic neurotransmitters are thought to have additive effects on the treatment of pain. Selective serotonin reuptake inhibitors do not possess these properties, but they can be effective in managing pain-associated depression with relatively

fewer side effects. Topical therapies such as capsaicin, lidocaine patch, diclofenac gel, and others may be useful for certain localized pain syndromes, such as postherpetic neuralgia or osteoarthritis.[36] Long-term use of benzodiazepines usually should be avoided because of the potential risk of adverse effects. Some states have passed laws that allow for the use of marijuana for chronic pain.[25] There are plausible mechanisms by which cannabinoids might produce analgesia.[26] However, given the limited data on the efficacy and safety of marijuana and the persistent legal controversies concerning its use, it is unlikely to play a central role for most patients.

Opioids

Opioids are effective treatment for nociceptive or neuropathic pain, as well as pain caused by mixed etiologies, such as cancer.[37] Criticism of the studies of opioid use reflect that the efficacy trials were short in duration, sponsored by pharmaceutical companies, excluded patients with histories of substance use or mental health conditions, and did not follow rigorous outcomes such as improved function, using subjective pain scores instead.[38] Patients taking higher dosages of opioids have poorer functional status and lower quality of life compared to those not taking opioids or using low-dose regimens. After adjusting for disease state, patients on opioids also have greater self-reported disability than those not taking opioids.[39]

Opioids-associated morbidity and mortality—The dramatic increases in prescription drug overdose death, injury, and substance use observed over the past decade in the United States have driven increased scrutiny of opioid-prescribing practices. Substantial increases in opioid prescribing and sales have paralleled the surge in drug-associated morbidity and mortality (Figure 38-2). This phenomenon has not been reported in the European Union or countries outside of the United States.[40] Interestingly, the United States consumes 80% of the world's supply of prescription opioids.[41] In fact, in the United States, 693 mg morphine equivalents of strong opioids were prescribed per capita in 2010, compared to 335 mg per capita in the United Kingdom, 205 mg per capita in the Netherlands, and 144 mg per capita in Italy.[42]

Opioid prescribing—Given this public health risk, there has been a new focus on safe opioid prescribing including careful risk assessment prior to starting therapy, close observation of patients on treatment, and discontinuation of medication if there is no improvement or evidence that opioids may be causing harm. Guidelines for managing chronic opioid therapy generally concur that high doses (defined as ≥200 mg morphine equivalents per day) or concomitant use of other sedating medications or substance use requires caution. Use of methadone with other opioids or benzodiazepines poses safety risks.

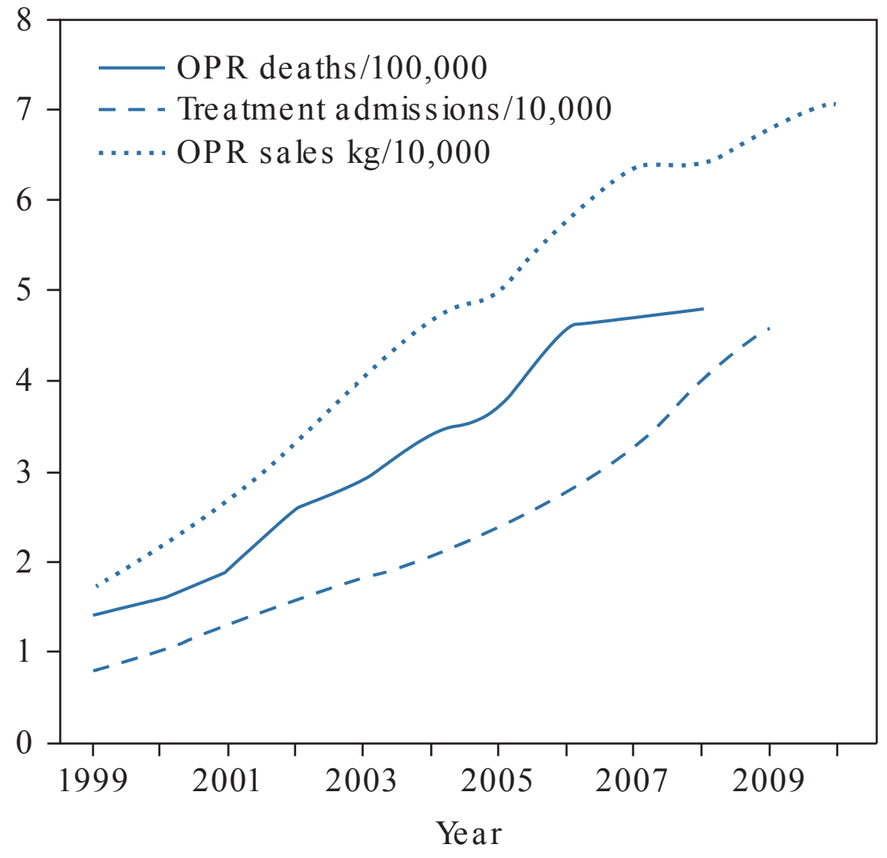


Figure 38-2. Rates of prescription painkiller sales, deaths, and substance abuse treatment admissions (1999–2010). Sales: The rate of prescription painkiller sales increased from less than 2 kg per 10,000 people in 1999 to more than 7 kg per 10,000 people in 2010. Deaths: The rate of prescription painkiller deaths increased from less than two deaths per 10,000 people in 1999 to more than four deaths per 10,000 people in 2008. Admissions: The rate of prescription painkiller treatment admissions increased from less than one treatment admission per 10,000 people in 1999 to more than four treatment admissions in 2009. (From Centers for Disease Control and Prevention (CDC). Rates of opioid pain reliever (OPR) overdose death, OPR treatment admissions, and kilograms of OPR sold—United States, 1999-2010. MMWR Morb Mortal Wkly Rep 2011; 60:1487-1492. Available at http://www.cdc.gov/vitalsigns/PainkillerOverdoses/index.html.)

Despite lack of strong evidence for doing so, use of risk assessment tools, agreements, and urine drug testing are generally recommended for monitoring patients. Many guidelines exist, with the American Pain Society-American Academy of Pain Medicine (APS-AAPM)'s guideline being evidence based and often cited[43,44] (see the CDC link in the "Resource" section for a comparison of many guidelines). Importantly, many health coverage payers have begun to require elements of these recommendations—for example, dose limits, treatment agreements, urine toxicology testing—for reimbursement.

Both short- and long-acting opiate preparations can be prescribed for refractory pain. Short-acting opioid preparations can be useful for treating pain that is sporadic or intermittent. For constant pain, once a stable daily opioid requirement has been established using short-acting opioids, a switch can be made to longer-acting opioids (e.g., sustained release morphine, fentanyl patch). Because of the unpredictable half-lives of their metabolites, long-acting opioids should be introduced at low doses and tapered

up gradually over several days or weeks. Simultaneously, short-acting opioids should be tapered down, and reserved for occasional or episodic breakthrough pain. While this is common practice for chronic pain, there is no evidence supporting long-acting opioids' superiority over short-acting forms in functional outcomes or reducing side effects or addiction.[45]

Opioid side effects—Constipation is probably the most common adverse effect of opioid therapy, and may lead to bowel obstruction if not treated proactively. When opioids are prescribed, a simultaneous prescription for a laxative, such as senna, in combination with a stool softener, such as docusate sodium, should be part of the regimen. However, fiber-based bowel preparations should be avoided as a sole treatment for constipation in these patients, because they may increase the bulkiness of stools without promoting bowel motility.

Nausea and vomiting also are common opioid side effects, although these usually can be managed by titrating opioid doses slowly and coadministering antiemetics such as ondansetron or metoclopramide when needed. Pruritus is a less common side effect, but can occur, and is difficult to treat. Opioid antagonists have shown efficacy, but are associated with decreased analgesic effect. Anti-histamines have limited efficacy and are sedating.[46]

Sedation, another common side effect of opiate medications, usually dissipates over time and most patients on a stable dose of opioids are able to engage in their usual activities, including driving or operating machinery after adjusting to a stable dose.[47] Respiratory depression is uncommon when opioids are begun at low doses, titrated slowly, and taken as directed. Despite this, there is ample evidence that patients taking chronic opioids for pain are at risk for unintentional overdose. Additional risk factors include significant medical illness (i.e., obstructive sleep apnea, Chronic Obstructive Pulmonary Disease [COPD]), comorbid mental health conditions, any history of a substance use disorder, use of methadone and other extended-release formulations, high daily dosage, and use of opioids with other sedating medications including alcohol and benzodiazepines.[48]

Patients should understand the safety risks associated with these medications. Providers should inquire about the way a patient takes his or her medication and how to protect themselves against harm. Notably, pain management programs in areas with high prescription drug overdose rates that have begun distribution of naloxone to patients on chronic opioid therapy have documented reductions in death. It is unclear if this is due specifically to naloxone distribution or the increased efforts around prevention and education.[49]

Opioid-induced endocrinopathy, or opioid-induced hypogonadism, is also recognized as a potential side effect of chronic opioid therapy, most commonly observed with use of long-acting preparations. Thought to occur because of the inhibitory effects of opioids on gonadotropin-releasing hormone secretion in the hypothalamus, the effect has been observed in both men and women. In a study of chronic pain patients taking opioids for more than 1 year, 80% of male patients had reduced serum testosterone and significant sexual dysfunction, and 87% of females younger than 50 had amenorrhea with decreased estradiol levels. [50] Testing with a total morning testosterone or estradiol level may be warranted if patients are on long-acting agents or exhibit symptoms of hypogonadism (i.e., fatigue, decreased libido, amenorrhea, osteoporosis).[51]

Higher doses of opioids may have neurotoxic effects such as hyperalgesia or delirium. Opioid-induced hyperalgesia (OIH) refers to the state of increased perception of pain due to opioids in the absence of disease progression or opioid withdrawal. While poorly understood, the underlying etiology is thought to include a direct effect of opioids in increasing the activity or sensitivity of pronociceptive pathways. In practice, this can be diagnosed by a therapeutic trial of dose reduction to see if this alleviates pain.[52]

Special considerations when prescribing opioids—Some physicians refuse to prescribe potent or long-acting opioids for chronic nonmalignant pain under any circumstances. An understanding of the true risks and potential benefits of opioids in selected patients with intractable pain should enable physicians to overcome ill-founded barriers to the use of opioids for legitimate pain relief. For example, physicians often cite fear of medication tolerance or physical dependence as a reason not to prescribe opioids for chronic pain.[53,54] Both effects can certainly result when opioids are dosed around the clock. However, these effects can often be managed safely and should not be a contraindication to the use of opioids in patients who have significant pain that is refractory to other treatments.

Medication tolerance is a state in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time. Most chronic pain patients can be managed on stable doses for months or years without the development of tolerance. Although tolerance may occur, it is not necessarily an indication that continued use of opioids is contraindicated. In addition, diminishing pain relief may be an indication that the underlying disease process has gotten worse, rather than secondary to the development of tolerance. Tolerance also raises the doses of opiates required to achieve adequate pain control in the treatment of acute pain for those who use opiates chronically in any form, that is, prescription medications, heroin, or methadone use.

Physical dependence occurs when a withdrawal syndrome can be produced by abrupt cessation or rapid dose reduction of a drug. Opioid withdrawal can be very unpleasant for patients, but usually it can be avoided

by tapering opioids slowly when indicated, and it is not a contraindication to the use of opioids in chronic pain patients.

Substance use disorders, concerning behaviors, and diversion—A substance use disorder is a set of behaviors distinguished by persistent craving of a drug, compulsive use, or continued use of a substance or drug despite evidence of harm. In the latest Diagnostic and Statistical Manual, version 5 (DSM-5), the diagnostic criteria for substance use disorders no longer include the distinction between abuse and dependence. Grading the severity of the disorder is highlighted instead. For example, patients are diagnosed with an opioid use disorder that is mild, moderate, or severe depending on the number of diagnostic criteria observed (Table 38-2).

Importantly, for patients taking chronic opioid therapy for pain, the criteria of tolerance and withdrawal are not counted toward a diagnosis, as these are expected to occur with treatment. A challenge for the provider is determining when a patient taking chronic opioids for pain may be developing a substance use disorder. Estimates of the percentage of patients on chronic opioid therapy who develop an opioid use disorder are highly variable, ranging from 0% to 45% of patients.[55] Use of opioid medications, particularly at high doses chronically, has been strongly associated with development of an incident opioid use disorder.[56] In addition, patients with a history of mental health disorders and substance use appear to be at highest risk for developing subsequent addiction.

Many patients taking chronic opioid therapy may develop one or more "concerning behaviors" or "yellow" or "red flag behaviors." These can be variable, and include abusive or manipulative behavior, abnormal urine toxicology testing, requests for early refills, or attempts to receive opioids from several providers simultaneously. There are no consensus guidelines on how to respond to concerning behaviors, likely due to the broad range of abnormalities. Importantly, any concerning behavior has its own differential diagnosis. The behavior may be due to a substance use disorder, diversion of the medication, pseudo-addiction, self-treatment of a mood or anxiety disorder, lack of efficacy of the medication, opioid-induced hyperalgesia, an acute pain process, or tolerance. For example, a patient with lumbago taking chronic opioids may seek prescriptions from several providers because she has a new compression fracture. Alternatively, the patient may be seeking multiple prescriptions because she can no longer control her use. Pseudo-addiction refers to the patient who exhibits "addictive behavior," which is actually due to undertreated pain. Pseudo-addiction can be diagnosed with a trial of a dose increase, which may result in resolution of the behavior.

It can be challenging to determine if a patient's concerning behavior does in fact reflect a new opioid use disorder. In general, an opioid use disorder is characterized by hazardous use, inability to control one's use, and compulsion to use causing social dysfunction. There are various tools to aid in this diagnosis. First, having a longitudinal relationship with the patient is important for characterizing a pattern of abnormal behavior. Second, collaborating with colleagues in behavioral health and addiction medicine can be helpful. Clinics may also develop internal review committees where patient's cases are presented and the provider can receive peer feedback. Third, various monitoring tools can be used such as random urine toxicology testing, pill counts, and review of a prescription activity report, which is available on a state-by-state basis.

Patients with a history of past or current substance abuse may legitimately warrant the use of opioids for chronic pain, but they also require careful evaluation of their pain syndrome, history with prescribed opioids, and current addiction status. There is evidence that buprenorphine-naloxone may be beneficial for patients with comorbid opioid use disorders and chronic pain.[57] This medication is currently not FDA approved for use in chronic pain, but this is an area of active research and interest. An evaluation by an addiction specialist knowledgeable in issues related to pain is very desirable.

Diversion of prescription opioids is an important law enforcement and public health problem in many communities. Diversion may be suspected when a patient's urine toxicology tests consistently fail to demonstrate presence of the prescribed medication, or reveal an illicit substance. Other red flags for suspected diversion include presentation to clinic or the emergency department intoxicated, requests for particular brands or dosage of medication, and refusal to discuss alternative treatment options.

Table 38-2. DSM-5 Criteria for Diagnosis of an Opioid Use Disorder

Diagnosis requires at least 2 of 11 criteria to be present. Severity is graded by the number of criteria present: mild (2–3 criteria), moderate (4–5 criteria), and severe (6 or more criteria). Criteria can be clustered into the following four groups:

I. Impaired control:
(1) Taking more or for longer than intended
(2) Unsuccessful efforts to stop or cut down use
(3) Spending a great deal of time obtaining, using, or recovering from use
(4) Craving for substance

II. Social impairment:
(5) Failure to fulfill major obligations due to use
(6) Continued use despite problems caused or exacerbated by use
(7) Important activities given up or reduced because of substance use

III. Risky use:
(8) Recurrent use in hazardous situations
(9) Continued use despite physical or psychological problems that are caused or exacerbated by substance use

IV. Pharmacologic dependence:
(10) Tolerance to effects of the substance
(11) Withdrawal symptoms when not using or using less.

From a public health point of view, the greatest fear is that potent opioids will be taken by nontolerant persons or with other medications or drugs causing overdose or death. In contrast, chronic pain patients who have no prior history of substance use disorders generally have a lower potential for addiction. Clinicians should make sure that patients understand the relatively low potential for abuse in this situation, because a patient's fear of addiction may prevent him or her from accepting opioids even when they could be beneficial.

Preventing misuse or diversion—When prescribing opioids, assessing the patient's risk of developing opioid misuse may reduce the risk of unwittingly exacerbating a substance use disorder or facilitating diversion. Patients who are younger in age, have a history of a substance use disorder, or a mental health condition are at increased risk of developing concerning behaviors. Risk also can be assessed with a questionnaire based on subjective (i.e., Screener and Opioid Assessment for Patients with Pain [SOAPP], Pain Medication Questionaire [PMQ]) or objective information (i.e., The Diagnosis, Intractability, Risk, Efficacy [DIRE] score, and Opiate Risk Tool [ORT]). If a patient is at high risk, or has an active mental health or substance use disorder, the provider should offer nonopioid treatments for pain, and, if relevant, refer the patient to substance use treatment. If a trial of opioids is considered, it is important to explain the potential risks and benefits of opioid medications, and set out clear guidelines and consequences for the use or misuse of chronic opioid prescriptions. Several clinics have developed treatment agreements that patients must sign. While there is no evidence that agreements prevent addiction or harm, they are useful tools to clarify expectations for patient and clinician (i.e., see examples of treatment agreements available on the Internet, including the University of Michigan pain guidelines and the Interagency Guideline for opioid use from the Agency Medical Directors' Group). Sample elements are also shown in Table 38-3.

Opioid prescriptions should be logged and documented in the clinical record so that clinicians and staff who work together can easily monitor the amount of drug prescribed or dispensed. Patients should be seen frequently, especially when opioids are initiated, to monitor efficacy and side effects. If a patient fails to show pain relief or functional improvement, opioids should be discontinued, as opposed to increasing the dose. Avoid prescribing opioids to patients without complete or current clinical information (e.g., over the telephone or in on-call situations). Establish a single clinic or clinician as the sole

Table 38-3. Sample Provider/Patient Agreement for Controlled Substances for Pain[a]

I, …(patient name) …and …(provider name) …have decided to use a controlled substance for management of chronic pain or other medical condition caused by _____.

Good faith efforts to diagnose and treat the condition have been done and will continue. Appropriate consultations will occur when indicated. This treatment will not be a substitute for other modalities, including nonpharmacologic therapy.

The current medications are:

Medication	Instructions	Number/week/month	Start date	Discontinued

- I agree to other pain management strategies as necessary.
- I agree that I will reliably attend my appointments with the health-care provider.
- I agree that this medication will be used only by me.
- I agree to take this medication as prescribed.
- I agree that I will notify the prescriber if I have side effects from the medication (e.g., sedation) and will not drive or operate machinery while taking this medication if feeling impaired.
- I understand that if I run out of medication because I increased the dose without speaking to the prescriber, the prescription will not be filled early.
- I understand that spilled, lost, or stolen medications will not be replaced.
- I will not seek controlled substances from other sources.
- Pharmacy records may be reviewed to confirm prescriptions.
- Medications will be refilled only during usual office hours.
- Urine or blood screening may be performed randomly for drug testing.
- This contract will be reviewed every __ weeks/months.
- Other terms:

Consequences: If any of the preceding rules are broken, medications will no longer be prescribed.
Signatures of provider and patient, with dates

[a]Adapted from the Community Health Network and San Francisco General Hospital Medical Center Controlled Substance Contract.

prescriber of opioids by setting and communicating clear rules from the outset with the patient and other clinicians caring for the patient. Although pain medicine, addiction medicine, and subspecialty resources may be limited in many communities, clinicians should not hesitate to pursue consultation with a specialist as a precondition to the continued prescription of opioids, especially for patients with aberrant behaviors or suspected drug abuse. Most states now offer clinical databases on patients prescribed controlled substances that can be consulted if a clinician suspects unauthorized use of multiple prescribers or "doctor shopping."

Mandatory random urine drug testing can be a useful tool for monitoring both the presence of unexpected drugs of abuse and the absence of prescribed opioids.[58] Importantly, concerning behaviors in the clinical setting are not predictive of abnormal urine toxicology testing, and vice versa.[59] Discussing the consequences of unexpected results before they occur is useful. For example, continued prescription of opiates might be made contingent on the patient entering substance use treatment.

When performing urine drug testing, it is important to understand how to interpret the testing that is performed by your local laboratory. Most urine toxicology tests are done via rapid immunoassays, which may or may not detect synthetic (i.e., methadone) and semisynthetic (i.e., oxycodone) opioids. Confirmatory testing is done with mass spectroscopy or high-performance liquid chromatography. Interpretation of results is often dependent on having knowledge of basic opioid metabolism as several opioids are converted to other prescribed opioids. For example, if a patient is prescribed codeine and a urine toxicology test returns positive for morphine, the prescriber may erroneously assume the patient is taking morphine when in fact it could be a normal metabolite. Similarly, many immunoassays for amphetamines may be falsely positive due to other prescribed medications (e.g., trazodone), and if not confirmed by mass spectroscopy, it may lead to inappropriate accusations of substance use. Consultation with a local lab medicine or toxicology clinician can be helpful to ensure that the test is interpreted correctly.

Certain patients may require discontinuation of opioids because of concern for an opioid use disorder, diversion, or lack of efficacy. There are no evidence-based guidelines describing a specific schedule, but existing resources on pain management often recommend a taper of 10% of the original dose every week until 20% remains, and then tapering the remaining 20% by 5% of the original dose each week until off or at goal.[60] Patients often require increased emotional support during opioid tapers, and may also need to be prescribed as-needed agents for symptoms (e.g., trazodone for insomnia). Use of buprenorphine in these situations is also favored. Patients must be reassured that treatment for their pain and other health problems is not being stopped but requires changes and more intensive focus on nonopioid and nonpharmacological measures.

Medicolegal issues and documentation requirements—Many physicians are reluctant to prescribe opioids because of rare but well-publicized cases of inappropriate investigations by the US Drug Enforcement Agency. At the same time, there also has been a public outcry about the undertreatment of pain triggered by patients who have successfully sought damages for inadequate pain treatment through the courts.

In 1998, in order to encourage the appropriate use of opioids when indicated, the Federation of State Medical Boards published guidelines for the use of controlled substances. Given the evolution in the field, these guidelines were updated in 2004 and 2013. The newest guidelines recommend a thorough patient evaluation of the pain, and any concomitant mental health or substance use conditions; development of a treatment plan and goals; use of written informed consent and treatment agreements; use of an opioid trial before starting chronic therapy; ongoing monitoring of function and adaptation of the treatment plan; periodic drug testing and review of prescription drug monitoring reports; consultation with pain or addiction specialists as needed; discontinuation of opioids if risks outweigh the benefits; and requirements for medical record keeping.[61] Additional resources can be found here at http://www.fsmb.org/pain-resources.html.

CONCLUSION

> Two months later, JP comes to your office for follow-up. He has increased his dose of gabapentin and has been attending regular Alcoholics Anonymous meetings. His pain is still present, but he is finding it more manageable, and has started spending time with his grandchildren again. He says that every day is a "real struggle" but he is getting by pretty well. He is most proud that he has cut back his alcohol use and been able to spend time with his family again.

While chronic pain can be viewed as a challenging task for the busy clinician, it can also be seen as an opportunity to build a very strong, longitudinal relationship with your patient. The biopsychosocial model of pain posits that patient suffering is often influenced by a multitude of factors, including physical disease, emotional stress, and structural forces such as poverty and inequality. Given the complex nature of pain, it is the role of the provider to build trust with the individual and work together to explore multiple modalities of treatment. Well-informed clinicians can contribute greatly to the amelioration of chronic pain among their patients. On a broader level, clinicians can be important advocates for appropriate pain management

resources within health-care organizations that provide services to medically underserved communities.

- Ask your patients about pain or you may never know about it.
- Understand the context and meaning of pain for the patient, and diagnose comorbid conditions such as depression or substance use disorders.
- Create a goal-oriented treatment plan to address the underlying cause of pain, the level of pain, and the functional limitations caused by the pain.
- Periodically review the treatment plan to make sure it remains realistic and relevant to patient goals.
- Treatment of chronic pain is often a trial-and-error process and should involve multiple treatment modalities.
- An understanding of the potential risks and benefits of opioid therapy can help primary care clinicians rationally select and safely monitor patients who may benefit from them.
- Opioids can be prescribed to patients with intractable pain and a history of substance use disorder, provided that close monitoring and specialty evaluation are included in the treatment plan.
- Explicit office policies, written agreements, prescription drug logs, and random urine drug testing can support clinicians and patients in adhering to treatment guidelines.
- At every visit in which opioids are prescribed, document the five As: analgesia, activities of daily living, adverse effects, aberrant behaviors, and affective disorders.

Management of Chronic Pain

- Ask about pain. Use a scale, monitor treatment effectiveness.
- Successful pain management requires several issues to be addressed simultaneously:
  —The underlying cause of pain
  —The pain itself
  —Functional limitations caused by the pain
  —Comorbidities such as depression or substance use disorders that make treatment more complex
  —Contextual issues such as employment, insurance, cultural beliefs, and social supports that may influence the ability to obtain appropriate care
- A therapeutic alliance is especially important.
  —Trust, realistic expectations and mutual goals are important
- Treatment of chronic pain often involves trial and error.
  —Distinguish between nociceptive, neuropathic, or mixed etiologies of pain.
  —Base treatment on etiology of pain.
  —Use adjuvant treatments.
  —Consider specialty consultation.
- Opioids can be effective medication for chronic pain, but must be prescribed with care.
  —Manage side effects.
  —Constipation may be prevented with docusate and senna.
  —Itching may be prevented or treated with antihistamines.
  —Nausea can be treated with antiemetics or by changing to a different opioid.
  —Watch for tolerance and dependence when prescribing opioids—but recognize that these are not contraindications to use!
  —Consider written agreements and random urine drug testing.
  —Monitor pain.
  —Use equianalgesic dosing when converting medications.
- Address and document the five As at each clinical visit:
  —Analgesia.
  —Activities of daily living.
  —Adverse effects.
  —Aberrant behaviors.
  —Affective disorders.
  —Warn patients to keep medications out of reach of children.
  —Consider prescribing naloxone to patients on high doses, histories of substance use or overdose or medical illnesses.

DISCUSSION QUESTIONS

1. Discuss the reasons why chronic pain is more prevalent in medically underserved populations.
2. What can you do in your own practice to make it easier for your patients to talk to you about pain?
3. What practice tools can help you manage pain once it is recognized?
4. If JP's pain were more severe or persistent, would you have prescribed long-acting opioids? Why or why not? If so, how would you have monitored his care?

RESOURCES

The American Academy of Pain Medicine: http://www.painmed.org.

American Pain Society: http://www.ampainsoc.org.

American Society of Addiction Medicine: http://www.asam.org.

Pain and Policy Studies Group: http://www.medsch.wisc.edu/painpolicy/.

CDC Comparison Chart of Opiate Prescribing Guidelines: http://www.cdc.gov/homeandrecreationalsafety/pdf/Recommendations_in_Opioid_Prescribing_Guidelines_for_Chronic_Pain.pdf).

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Chapter 39

Principles of Caring for People Who Use Alcohol and Other Drugs

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Objectives

- Define substance use disorders.
- Describe the burden of substance use on individual and public health.
- Outline barriers and facilitators to good patient care.
- Describe screening, brief intervention, and patient communication techniques.
- Review effective pharmacologic and nonpharmacologic treatments.

INTRODUCTION

Mr. Wayland is a 45-year-old disabled ironworker. He presented to the emergency department after an auto accident. He was hospitalized when he began to show signs of alcohol withdrawal. While hospitalized, he learned that he had hepatitis C infection.

Alcohol and drug use burdens individuals and society the world over through its association with acute and chronic illnesses such as overdose, trauma, liver disease, and human immunodeficiency virus (HIV) infection, and its connection to social problems, such as family violence, homelessness, and poverty. Neuropsychiatric illnesses are the largest contributors to the global burden of disease, with substance use second only to depression as a specific causative factor.[1] The contribution of substance use to mortality and morbidity varies by country (for country-by-country statistics, see WHO interactive maps at http://gamapserver.who.int/gho/interactive_charts/substance_abuse/treatment_alcohol_drugs/atlas.html) and by state in the United States (http://nccd.cdc.gov/DPH_ARDI/default/default.aspx).

Stigmatization of people who use substances by society in general and the health-care system in particular compounds these burdens. An estimated 22.2 million US citizens suffer from alcohol and drug use disorders.[2] The annual economic cost of alcohol use disorders in the United States alone has been estimated at greater than $223.5 billion dollars.[3] Although tobacco use is the leading cause of preventable death in the United States, the nature of addiction to alcohol and drugs reduces patients' ability to function and reduces providers' desire to provide care, making alcohol and drug use disorders a vulnerability in a way that smoking is not. Hence, this chapter focuses primarily on addictions other than smoking, although much of what is presented here can be used to address cigarette use as well (see Chapter 40). This chapter describes the individual and societal burdens of alcohol and drug use with a focus on substance use in the United States, and provides specific strategies to address substance use disorders and advocate for patients.

THE SPECTRUM OF SUBSTANCE USE

People often begin using alcohol or drugs because they believe it will make them feel better. Those who are physically dependent on alcohol or drugs use them to avoid

withdrawal. Others with underlying disorders such as chronic pain, schizophrenia, and posttraumatic stress disorder may use substances to cope with the symptoms of these conditions.[4] Clarifying the nature and consequences of use for each patient and then diagnosing substance use disorders will guide clinicians' prevention and treatment efforts.

Limited use of alcohol is associated with health benefits such as decreased risk of heart disease. However, recommending alcohol for its potential health benefits is controversial because it is very difficult to determine whether the potential benefits exceed the concomitant risks. Studies, other than randomized controlled trials, which have not been done, are limited by issues of bias and confounding.

AT-RISK ALCOHOL USE

To distinguish between safer and hazardous or harmful alcohol use, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) has defined moderate drinking (i.e., safe) as two drinks or fewer (12 oz. of beer, 4 oz. of wine, or 1.5 oz. of liquor) per day for men younger than 65 years, and one drink or fewer per day for women and people older than 65 years. The NIAAA defines at-risk drinking as more than 14 drinks per week or 4 drinks on any one occasion for men, and more than 7 drinks per week or 3 drinks on any one occasion for women. Patients in the at-risk drinking category are at greater risk for all-cause mortality and have a greater risk for developing a use disorder.

There are no similar "at-risk" definitions for drug use, perhaps because of the wide number and types of illicit drugs and the many ways they are used and abused.

MEDICAL MARIJUANA

An increasing number of states are permitting the distribution and use of medical marijuana for the relief of symptoms from chronic conditions, such as anorexia, nausea, anxiety, and chronic pain. Washington and Colorado have fully legalized and regulated the sale of recreational marijuana. Use of medical marijuana typically requires approval by a physician that permits patients to either grow it themselves or obtain it from a state-regulated dispensary. Marijuana users and medical providers prescribing or sanctioning its use are operating in a space of legal limbo between the federal government and approving states, because marijuana remains classified at the federal level as a substance with no medical benefits. There is some evidence for the symptom-relieving benefits of marijuana, yet there are substantial concerns about the adverse effects of chronic marijuana exposure, particularly for the developing brains of adolescents and young adults.[5] Specifically, regular marijuana use during adolescence has been associated with worse cognitive function and development of addiction to marijuana and other substances. Acute marijuana use impairs driving ability and increases the risk of vehicle crashes.

SUBSTANCE USE DISORDER DIAGNOSES

The American Psychiatric Association (APA) updated its diagnostic criteria and definitions for substance use disorders in 2013 (Box 39-1). This update integrated two previous disorders—substance abuse and substance dependence—into one disorder with three subclassifications of mild, moderate, and severe, based on the number of the 11 criteria that a person meets in a 12-month period.

Box 39-1. DSM-5 Criteria for a Substance Use Disorder

Subclassification

Mild = 2–3 criteria, Moderate = 4–5 criteria, Severe = 6 or more criteria

A. Impaired control:
   1. Taking more or for longer than intended
   2. Not being able to cut down or stop (repeated failed attempts)
   3. Spending a lot of time obtaining, using, or recovering from use
   4. Craving or strong desire to use a substance

B. Social impairment:
   5. Role failure (interference with home, work, or school obligations)
   6. Continued use despite relationship problems caused or exacerbated by use
   7. Important activities given up or reduced because of substance use

C. Risky use:
   8. Recurrent use in hazardous situations
   9. Continued use despite knowledge of physical or psychological problems

D. Pharmacologic dependence:
   10. Tolerance to effects of the substance[a]
   11. Withdrawal symptoms when not using or using less[a]

[a]Persons who are prescribed medications such as opioids may exhibit these two criteria, but would not necessarily be considered to have a substance use disorder.

Source: From American Psychiatric Association. Substance-related and addictive disorders. In: Diagnostic and Statistical Manual of Mental Disorders, 5th ed. Arlington, VA: American Psychiatric Association, 2013. doi:10.1176/appi.books.9780890425596.744053.

Mr. Wayland has at least a mild alcohol use disorder because he drinks despite harmful consequences (an auto accident) and he experiences withdrawal.

THE MAGNITUDE OF THE PROBLEM

Mr. Wayland started drinking alcohol at the age of 13. When he was working, he was fired twice for being late. After being injured at work 15 years ago, he began taking prescription pain medicines. At times, these medicines did not adequately control his pain and he started using heroin in addition to his daily drinking. Before qualifying for disability, he was homeless for a year.

For the year 2012, the National Survey on Drug Use and Health (NSDUH) estimated that 23.9 million people used illicit drugs and 125.5 million people drank alcohol in the previous month. Of the estimated 22.2 million Americans with a substance use disorder, 14.9 million have an alcohol disorder only, 4.5 million have a drug use disorder only, and 2.8 million have both alcohol and drug use disorder.[2] Only 2.5 million people receive specialty addiction treatment for substance use disorders. Surveys in primary care settings find rates of 2–29% for alcohol use disorders,[6] 5–9% for current drug use disorders, and 20–25% for lifetime illicit drug use.[7]

Concomitant alcohol and drug disorders often go unnoticed in primary care and drug treatment programs, yet "polysubstance" users have greater physical and mental health problems and higher mortality than single substance users.[8,9]

HEALTH CONSEQUENCES OF ALCOHOL AND DRUG USE

Mr. Wayland has had multiple visits to the emergency room and admissions to the hospital for trauma, alcohol withdrawal, pancreatitis, and cellulitis. Although never diagnosed with a mental illness, he overdosed on heroin after his divorce.

Substance use disorders exacerbate other vulnerabilities such as race and ethnicity, poverty, mental illness, and chronic disease. People who use alcohol or drugs are at significantly higher risk for death at a younger age than abstainers. These deaths result from accidental overdose, violence, and chronic diseases, and result in large numbers of years of life lost.[10,11]

MEDICAL COMPLICATIONS

Medical complications of alcohol and drug use include both acute and chronic problems. Acute problems include overdose, seizures, psychosis, endocarditis, pulmonary edema, soft-tissue infections, osteomyelitis, hepatitis, pancreatitis, rhabdomyolysis, and sudden death. With chronic use, drug and alcohol addicts are at risk for chronic illnesses. Daily alcohol use of more than two drinks per day results in a twofold higher risk of hypertension; three- to fivefold higher likelihood of oral, esophageal, and liver cancer; and a ninefold higher risk of cirrhosis.[12] About half of all cirrhosis-related deaths are linked to alcohol.[10] Cocaine is associated with accelerated atherosclerosis, dilated cardiomyopathy, and chronic pulmonary toxicity (including organizing pneumonia, interstitial pulmonary fibrosis, and bullous emphysema). Using injection drugs repeatedly such as heroin, cocaine, or methamphetamine is a major risk factor for HIV, and hepatitis B and C infections. Active alcohol and drug use also interferes with treatment of chronic diseases such as HIV infection.[13]

IMPACT ON THE FAMILY

Mr. Wayland's father died 5 years ago from alcoholic liver disease. His ex-wife is in recovery from alcohol addiction, and he has a brother in recovery from heroin addiction.

The consequences of substance use extend from substance users to their families and neighbors. Non–drug using individuals living with drug users are 11 times more likely to be murdered than those not living with drug users (see Chapter 35).[14] Estimates suggest that 60–75% of women who use substances suffer from partner violence, about three times the risk for women in general. The combination of sex, drugs, and violence brings increased risk for sexually transmitted infections and mental illnesses such as depression and posttraumatic stress disorder.[15]

Substance use disorders are family diseases both because of the profound burden they place on family function and because they are passed from one generation to the next through genetic and environmental means.[16,17] Children exposed to alcohol and drugs in utero risk problems such as fetal alcohol syndrome and low birth weight. In many families, alcohol use disorders, domestic violence, and child abuse are linked and lead to alcohol use disorders in offspring.[18]

IMPACT ON THE COMMUNITY

While the direct medical complications of substance use are tragic for users and their families, the burdens from trauma, violence, and crime affect entire communities.[19] Because of several decades of "War on Drugs" policies, substance use is a fundamental thread woven into the blanket of crime in the United States. In metropolitan areas across the country, 63–83% of people arrested test

positive for drugs.[20] In 2011, just under half of criminal sentences were for drug offenses.[21] Yet fewer than 11% of the prison population receives drug treatment while incarcerated.[22]

MENTAL ILLNESS

Links between substance use and mental illness abound (see Chapter 33). People who use substances are more than twice as likely to have a mental illness as people who do not use substances, and people with a mental illness are more than twice as likely to have substance use disorder. Teenage alcohol and drug use predicts both chronic substance use disorders and later development of adult mental illnesses.[23] One study among people who use drugs found that about half screen positive for depression.[24] People who use substances are more likely to commit suicide.[25] For example, the increased rates of suicide among American-Indian and Alaskan Native men are linked to increased rates of alcohol and drug use.[12]

DIFFICULTIES IN CARING FOR PEOPLE WITH SUBSTANCE USE DISORDERS

> Mr. Wayland has not seen a primary care provider for 15 years. He stopped seeing his regular doctor when she refused to give him pain medicine prescriptions because he regularly ran out early.

Providers seem to derive little satisfaction from treating patients with substance use disorders,[26,27] and this is likely to result in poor care. For example, although validated tools are available to screen for alcohol use disorders, providers do not often use them. Furthermore, providers frequently avoid making referral to treatment even when they identify a substance use disorder.[28] Clinicians' attitudes are not lost on substance using patients, who perceive that they receive poor access to care.[29] The alienation experienced by patients and providers can be explained by examining unrealistic expectations and mutual distrust.

HEALTH-CARE PROVIDERS' EXPECTATIONS

Patients who use substances may not fit health-care providers' expectations: they may be too intoxicated or substance dependent to have a clear presenting complaint; they may not permit testing or a thorough examination; a wide range of symptoms may reflect substance use and cloud diagnostic efforts; and they may refuse or be unable to follow treatment recommendations. In addition, providers may fear that patients will use prescribed pain relievers recreationally or sell them. Refusing to prescribe them, on the other hand, may lead to unnecessary suffering or even increased substance use. Finally, family or personal experiences with substance use may unconsciously influence the response to patients.

Box 39-2. Common Pitfalls in the Care of Substance Users

- Underdiagnosing and undertreating substance use disorders and their consequences
- Undermining the provider–patient relationship by mutual distrust
- Believing that success hinges on abstinence
- One provider trying to do all or all providers doing nothing
- Considering addiction a moral or character failing
- Perceiving relapse as failure
- Ignoring the risks of prescription medications that are commonly misused.
- Undertreating pain because of the concerns about triggering addiction

PATIENTS' EXPECTATIONS

The patient who uses substances may have unrealistic expectations about clinicians (Box 39-2). They may expect their pain to be treated promptly and resolve quicker than is possible. They may want to be treated as if they were not intoxicated. They may want immediate treatment for their addiction that is not available in many communities. Mistrust grows as patients become disillusioned with medical care they interpret as inconsistent or intentionally poor because of their substance use.[29,30]

ALCOHOL AND DRUG USE DISORDERS ARE CHRONIC, RELAPSING BRAIN DISEASES

> After the death of his father, Mr. Wayland detoxified from heroin and alcohol and went into a halfway house. He was abstinent and active in recovery support groups for 2 years until he relapsed to drinking. When asked about his drinking, he admits, "It's not fun anymore. I just drink to feel normal."

Substance use disorders have been stigmatized as a moral failing; however, it is now clear that the regular use of alcohol or drugs changes brain chemistry, neuronal structure, and function, driving a cycle of tolerance, withdrawal, craving, and relapse.[17,31] With repetitive use, euphoria wanes and people use alcohol or drugs to avoid withdrawal and because they crave them.

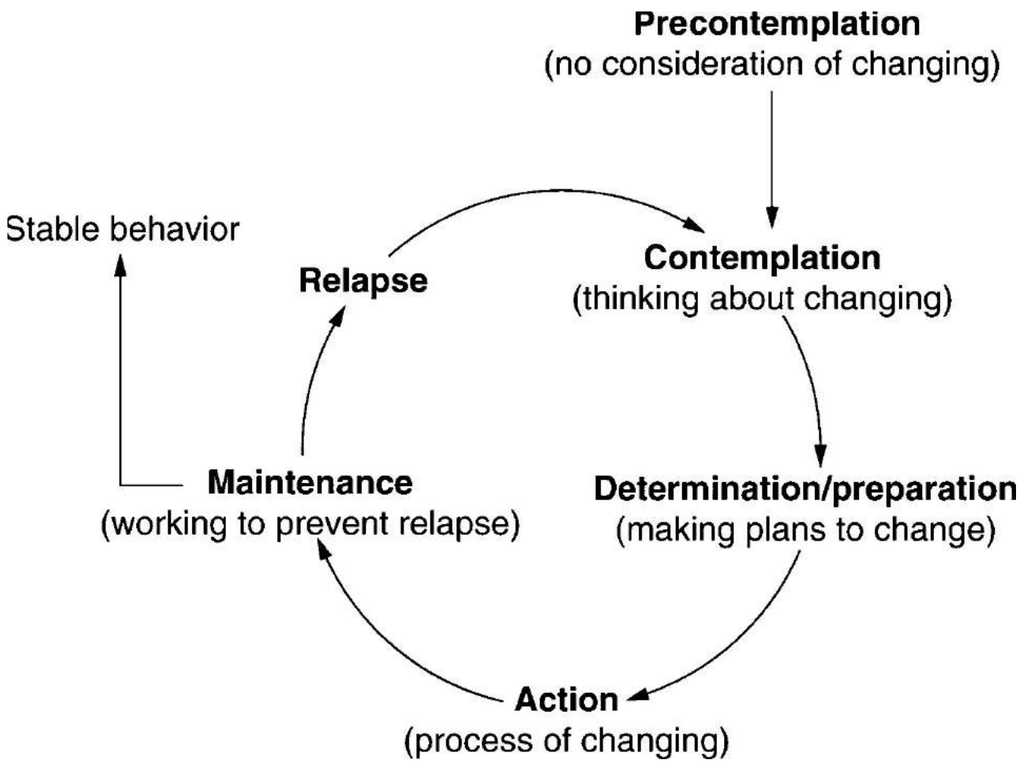


Figure 39-1. Prochaska and DiClemente's stages of change model. A theoretical model of behavior change that has been the basis for developing effective interventions to promote health behavior change (see text for details). The model is often considered cyclical because most people attempting to change their health behavior relapse and have to repeat stages in order to learn how to maintain their behavior.

Although a combination of motivation, social support, and medication often can help a person with substance use disorder into remission, the cycle of addiction remains hard wired and primed for relapse. As with other chronic diseases, such as diabetes, addiction is treatable but not curable. Treatment should be considered a lifelong commitment.

STAGES OF READINESS FOR BEHAVIORAL CHANGE

Although drug and alcohol use disorders are chronic brain diseases, they are also behavioral disorders for which providers should seek to facilitate change. Prochaska and DiClemente's "stages of change" is a model of behavior change that has been widely adopted among providers treating substance use disorders (Figure 39-1). This model identifies six stages that patients move through when changing behavior patterns (Box 39-3).[32,33]

HARM REDUCTION

Harm reduction is a treatment approach and set of strategies that aim to reduce the negative consequences of using substances.[34] It recognizes that although substance use causes harm, people who use substances are often not ready to abstain. In a practical sense, this means assessing those who are still using substances for the greatest risks to their health and working to collaboratively minimize them (Box 39-4). Clinicians should find ways to reduce the harms of substance use, helping patients make any positive change in substance use behavior that improves individual and community well-being. While abstinence from substances may result when people engage in harm reduction, improvement of quality of life is the primary goal. The approach is patient centered, recognizing that people who use substances are the primary agents of behavior change and calling for nonjudgmental, noncoercive services and resources. Successful applications of harm reduction programs include the implementation of needle and syringe programs for people who use injections drugs which have been shown in multiple studies to reduce the transmission of HIV infection,[35] and the distribution of naloxone rescue kits to people who use opioids and their social networks, which have been associated with reduced rates of opioid overdose deaths.[36]

Box 39-3. Stages of Behavior Change

- Precontemplation describes patients who deny they need to change or who feel hopeless.
- Contemplation describes patients who are ambivalent about change.
- Preparation or determination describes patients who have decided to change and are making plans.
- Action describes patients who are changing their behavior.
- Maintenance or recovery describes patients who have changed and are stable.
- When patients in recovery start using again they are in the Relapse stage, which typically leads to Contemplation and another progression through the stages.
- Representing the stages of change as a cycle (see Figure 39-1) follows from conceptualizing addiction as a chronic, relapsing disease. By determining the stage of change, the provider can use the appropriate interviewing strategy to engage the patient.

Source: From Samet JH, et al. Beyond CAGE. A brief clinical approach after detection of substance abuse. Arch Int Med 1996; 156:2287–2293; DiClemente CC, Velásquez MM. Motivational interviewing and the stages of change. In: W. Miller R, Rollnick S, eds. Motivational Interviewing: Preparing People for Change. New York: The Guilford Press, 2002:201-216.

Box 39-4. Conditions That Trigger Substance Use Screening

- Mental illness
- Legal, family, work, or school problems
- Trauma
- Perpetrating or sustaining violence
- Physical and laboratory signs such as elevated liver enzymes, or new HIV or HCV diagnoses
- Soft-tissue infections
- Sexually transmitted infections

ADDRESSING SUBSTANCE USE IN PRIMARY CARE

Treating substance use disorders has substantial potential for improving health. They can only be treated if they are identified and diagnosed. A patient, like Mr. Wayland, presenting to emergency department with obvious substance use consequences does not need to be screened. But many patients in primary care have undiagnosed substance use disorders. The United States Preventive Services Task Force (USPSTF) recommended in 2013 screening adults for alcohol misuse and providing brief behavioral counseling to reduce misuse in primary care.[37] The 2008 USPSTF review of screening and brief interventions for illicit drug use concluded that there is insufficient evidence to recommend screening for drug use.[38]

The NIAAA recommends a screening, assessment, brief counseling, and referral algorithm that starts a single screening question: "How many times in the past year have you had 5 or more drinks (for men) or 4 or more drinks (for women) in a day?" Any answer greater than zero is considered a positive screen, worthy of assessment, brief counseling, or referral to further treatment.[39] (See "Resources": "Helping patients who drink too much.") The National Institute on Drug Abuse recommends a similar screening, assessment, brief counseling, and referral approach for misused prescription and illicit drugs with the online NIDA Drug Screening Tool. (See "Resources": "NIDA Resource guide.") For both alcohol and drugs, the strategy is to ask about any use in the past year. Any positive responses should lead to assessment by asking about the DSM-5 diagnostic criteria. For patients who report no current or recent substance use, it is important to ask about a history of drinking or drug use in order to support their recovery.

Prognosis and intensity of treatment are determined in part by the severity of the substance disorder. With at-risk drinkers, providers should regularly address substance use and counsel to cut back or stop. Patients with a diagnosed substance use disorder should be offered referral for addiction treatment in addition to primary care–based brief intervention, as described in "Resources": "Helping patients who drink too much."[39]

BRIEF INTERVENTION: ADVISE TO QUIT AND DETERMINE READINESS TO CHANGE

Brief intervention is a technique based on motivational interviewing principles and relies on brief (i.e., 5–15 minutes) counseling sessions in which the provider expresses concern about the patient's substance use, gives feedback on the health risks of continued use, acknowledges that the patient may not see it as a problem, recommends cutting back and/or quitting, offers to help the patient change the behavior, and monitors use, consequences, and behavior changes at follow-up visits. Among people drinking at risky levels, behavioral counseling interventions result in a net reduction of 3.6 drinks per week (e.g., from 16 to 19 drinks per week) after 12 months of follow-up.[40] Implementing screening and brief intervention on a broad scale and among people who use drugs other than alcohol has not shown the same improvements as smaller controlled studies.[41,42] Thus, the optimal way to deliver brief interventions for people with drug use disorders awaits further research.

Once it is clear that a patient has a substance use disorder, the clinician should express concern about the alcohol or drug use and advise the patient to stop or cut back. Provider's advice to decrease use takes little time and is a useful and efficient way to assess a patient's readiness to change (see "Core Competency").

PRECONTEMPLATION: ADDRESS DENIAL AND RESISTANCE

Unfortunately, clinician's advice to stop or cut back does not often lead to an agreement between the provider and patient about a treatment strategy. When the patient is resisting the clinician's advice or denying he or she has a problem ("I am not addicted; I can quit any time"), further clinician's advice often begets more resistance and/or denial and potentially undermines the provider–patient relationship. In this precontemplative stage, a person is very unlikely to change his or her behavior. A more appropriate goal is to move him or her into a contemplative stage where the patient can acknowledge good and bad things about the behavior change the provider is advising. The underlying message to the patient should be one of support for the patient and his or her life ambitions, as well as encouragement to continue seeking care.

CONTEMPLATION: EXPLORE AMBIVALENCE

In the contemplation stage, the patient is aware that substance use is causing a problem but is ambivalent about quitting ("Part of me wants to stop, but I am not sure it will be worth it"). Clinicians should monitor patients' health and provide individualized feedback with re-enforcement and support for positive behavior change and acknowledgement of the negative effects of substance use with the goal of tipping patient ambivalence toward positive behavior change.

DETERMINATION: SUPPORT CHANGE

When the patient decides to get treatment ("I want to stop"), clinicians should praise the decision, assist the patient in choosing the right treatment, and obtain appropriate referrals. Choice of treatment for an individual

depends on the type and severity of substance use as well as the treatment resources available in the area.

ACTION

At this stage, the patient is in some form of treatment ("I stopped this week"). Communication among the provider, treatment program, and patient is extremely helpful and may be facilitated by more frequent office visits. Many patients may begin to notice symptoms that were masked by their substance use, such as pain or depression, and thus facilitating care for co-occurring vulnerabilities is important.

MAINTENANCE: RELAPSE PREVENTION

Providers often see patients for medical issues when the patient is recovering from a substance use disorder ("I have been clean and sober for 25 days"). Because primary care providers see patients over time, they are in a unique position to observe when a patient may be headed toward relapse, and preventing it should be a fundamental goal. Relapse prevention strategies include maintaining a therapeutic relationship and nonjudgmental attitude, communicating empathy ("that must be hard"), reinforcing positive behavior change ("I know you can do this"), identifying triggers, promoting coping strategies, and working with the patient's family. During this stage, most patients have a support network such as a social worker, counselor, Alcoholic Anonymous or Narcotic Anonymous sponsor, or family member who can help as they try to maintain abstinence. Providers should be familiar with local resources such as residential or daytime therapeutic communities focused on maintaining recovery.

Because addiction is a chronic, relapsing disease, relapse should be expected. The health-care provider can assist by reminding the patient that relapse is a normal part of recovery, the provider will not think less of the patient if he or she relapses, he or she will be seen promptly if a relapse occurs, and he or she will not be judged.

NONPHARMACOLOGIC OPTIONS

Counseling or talk therapy options for substance use that are evidence-based and more intensive then brief interventions include motivational interviewing,[43,44] cognitive behavioral therapy,[45,46] relapse prevention,[45] 12-step facilitation, contingency management,[47,48] and community reinforcement approach.[48-50] Although a single provider may be able to move a patient along the stages of change, patients will benefit from community-based substance treatment resources. Alcoholic Anonymous and Narcotics Anonymous are widely available group therapy abstinence programs that are self-supporting and nondiscriminating. Residential treatment programs, halfway houses and sober houses, where people in treatment and recovery live together, are particularly valuable resources for patients who are homeless or whose use is triggered by their residential environment. The treatment effectiveness of these programs may be confounded by the fact that more motivated patients enter treatment. Mandated or coerced treatment via criminal justice institutions such as drug courts, in which people charged with drug use–related crimes are offered treatment in lieu of incarceration, shows some promise[51,52] that warrants more implementation research.

Pharmacologic Treatment

Despite many randomized controlled trials examining antidepressants, dopamine agonists, antiseizure medicines, and long-acting stimulant replacement, no pharmacotherapy has been found effective for cocaine or methamphetamine use disorders.

Maintenance Treatment for Opiate Use Disorders

Methadone is a long-acting opioid agonist that reduces physical withdrawal and psychological craving in opioid-dependent patients. Methadone maintenance therapy (MMT) has been shown to reduce mortality, reduce HIV transmission, improve function and productivity, and reduce crime. A 1998 NIH Consensus Conference recommended access to MMT for all opioid-dependent patients.[53] MMT may only be distributed through federally licensed clinics; therefore, there are limited numbers of treatment slots.

Buprenorphine is a safe and effective, partial opioid agonist usually co-formulated with naloxone to deter diversion. It is taken sublingually. Physicians who complete an 8-hour training course may prescribe it. Because it is a partial agonist, it has a ceiling effect that reduces its abuse potential and the potential for respiratory depression. Both methadone and buprenorphine are effective for detoxification in addition to maintenance. Treatment with both should include counseling in addition to the medication itself.

Naltrexone is a long-acting opioid antagonistic that blocks the effects of opioids and reduces opioid craving. Both daily oral and monthly injectable formulations are available. Because of its opioid antagonism, patients must be completely abstinent from opioids through a detoxification program before initiating naltrexone. Otherwise, there is a high-risk of precipitated withdrawal.

Therapies for Alcohol Use Disorders

Naltrexone, an opioid antagonist; acamprosate, a gamma-aminobutyric acid analog; and gabapentin, an antiseizure medication, are effective at reducing craving and relapse in severe alcohol use disorder. They may be used alone or in

combination and should be considered adjuncts to a comprehensive treatment plan that includes counseling, group therapy, or self-help participation. Disulfiram reduces relapse in severe alcohol use disorder by causing adverse autonomic and gastrointestinal symptoms after drinking alcohol.

Detoxification

Although detoxification (detox) is rarely enough to maintain abstinence, it is often the first step to recovery, that is, action. Detox can occur with or without medical management. Detox from heavy alcohol use is best done with medical management in a supervised setting because of the risk of seizures, autonomic instability, and delirium. Opioid withdrawal may be treated with methadone or buprenorphine tapered over days to weeks. Although no medicines are reliably effective for stimulant withdrawal symptoms, temporary inpatient respite may be helpful for initiating treatment.[54]

> Mr. Wayland learns about hepatitis C from his primary care provider. They discuss his alcohol and heroin use and choose these as their focus. Over the next 2 years, he relapses on heroin a few times and he enters a methadone maintenance treatment. With support, he attends Alcoholic Anonymous regularly and decreases his alcohol use.

CONCLUSION

Providers who incorporate the stages of change model and harm reduction into their practices may feel greater satisfaction in caring for substance users. Providers' roles and expectations change, and as they support patients in the gradual process of quitting, providers can relish the small victories that occur.

Substance abuse, and its causes and consequences, is usually so complex that a single provider cannot address it alone. Care management teams that include drug and alcohol counseling, social workers, and psychiatrists have been shown to reduce substance use and its harms (see Chapter 16). If a formal care management team is not available, providers can try to assemble an ad hoc team by referring patients to treatment programs and community social service agencies. Sharing tasks, insights, and rewards, as well as frustrations increases the chances of successful treatment and is helpful to the medical provider.

As providers gain competency in caring for people with substance use, they will find that, as with all medical care, the most compelling reward is getting to know the patient and developing a relationship. Engaging with people as they struggle with addiction, sharing in the tragedy of continued use, and witnessing the triumph of recovery can be profoundly satisfying.

- Addiction is a chronic, relapsing brain disease.
- With support, patients have the potential to change their behavior.
- Establish trust as a first step to facilitating behavior change.
- Screen for at-risk use and substance use disorders.
- Express concern and advise the patient to stop or cut back.
- Assess the patient's readiness to change and use the appropriate interviewing approach.
- Assemble a care plan that accounts for:
  —Level of use
  —Readiness for change
  —Other vulnerabilities (i.e., mental illness, HIV infection)
- Recognize and acknowledge any positive change.

Interview Approaches Based on the Patient's Readiness for Behavior Change

Stage of Readiness	Interview Approaches
Precontemplation	• Express concern about the patient and substance use (SU). • State nonjudgmentally that SU is a problem. • Agree to disagree about the severity of the problem. • Consider a trial of abstinence to clarify the problem. • Suggest bringing a family member to an appointment. • Emphasize the importance of seeing the patient again.
Contemplation	• Elicit positive and negative aspects of SU. • Ask about positive and negative aspects of past periods of abstinence. • Summarize the patient's comments on SU and abstinence. • Clarify discrepancies between the patient's expressed values and his or her actions. • Consider a trial of abstinence.
Determination/ Preparation	• Acknowledge the significance of a decision to seek treatment. • Support self-efficacy. • Affirm the patient's ability to successfully seek treatment.

	• Help the patient decide on appropriate, achievable action. • Caution that the road ahead is tough but very important. • Explain that relapse should not disrupt the patient–clinician relationship.
Action	• Be a source of encouragement and support. • Acknowledge the discomforting aspects of withdrawal. • Reinforce the importance of remaining in recovery.
Maintenance/ Recovery	• Anticipate the difficulties as a means of relapse prevention. • Recognize the patient's struggle. • Support the patient's resolve. • Reiterate that relapse should not disrupt the medical care relationship.
Relapse	• Explore what can be learned from the relapse. • Express concern and even disappointment about the relapse. • Emphasize the positive aspect of the effort to seek care. • Support the patient's self-efficacy so that recovery seems achievable.

Source: Adapted from Samet JH, et al. Beyond CAGE. A brief clinical approach after detection of substance abuse. Arch Int Med 1996; 156:2287-2293.

DISCUSSION QUESTIONS

1. When seeing a patient with alcohol and cocaine use disorders, HIV infection, depression, and homelessness, how do you focus your efforts? What resources can you mobilize to help in this patient's care?
2. Five minutes into your first visit, a new patient accuses you of minimizing her pain and belittling her as an "addict." How do you begin to build trust?
3. If you were caring for Mr. Wayland as an inpatient, how could you use the described interviewing approaches during his inpatient stay? What is a realistic goal in addressing his motivation to change his substance use?

RESOURCES

Helping patients who drink too much: A clinician's guide, 2005 edition. National Institute on Alcohol Abuse and Alcoholism. National Institutes of Health. US Department of Health and Human Services. http://www.niaaa.nih.gov/guide.

NIDA Resource guide: Screening for Drug Use in Medical Settings. http://www.drugabuse.gov/publications/resource-guide-screening-drug-use-in-general-medical-settings/nida-quick-screen.

National Drug and Alcohol Treatment Referral Routing Service. 1-800-662-HELP or http://findtreatment.samhsa.gov.

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Chapter 40

Tobacco Use

Maya Vijayaraghavan, MD, MAS and Steven A. Schroeder, MD

Objectives

- Review the epidemiology of patients who smoke tobacco.
- Describe other types of tobacco used by vulnerable populations.
- Describe the health consequences of tobacco use and its impact on the health-care system.
- Describe the challenges that tobacco use poses to patients, clinicians, and communities.
- Identify strategies to treat tobacco dependence including clinical, policy-level, and systems-level interventions.

Clarence Jones is a 44-year-old man brought to the emergency room via ambulance in respiratory distress. He has had five admissions within the past year for chronic obstructive pulmonary disease (COPD) exacerbations and has been intubated during each admission. He has been smoking since he was 8 years old and smokes up to two packs a day.

INTRODUCTION

Cigarette smoking is the leading cause of preventable, premature morbidity and mortality in the United States and in many countries around the world. Smokers, on average, die 10 years earlier than nonsmokers.[1] Tobacco use is a major cause of death from cancer, cardiovascular disease, and pulmonary disease. Smoking accounts for 6% or more of total American medical costs.[2] Patterns of tobacco use are the result of the complex interactions of a multitude of factors, including socioeconomic status, culture, acculturation, poor access to medical care, targeted advertising, relative affordability of tobacco products, and varying capacities of communities to mount effective tobacco control initiatives.

It is clear that helping smokers quit may be the most important act health-care providers do. This chapter reviews the epidemiology, the health effects of cigarette smoking and other tobacco use, and the challenges to treating tobacco dependence, particularly among vulnerable populations where tobacco use is concentrated. It discusses some strategies for confronting these challenges.

EPIDEMIOLOGY OF TOBACCO USE

GENERAL EPIDEMIOLOGY

In 2012, an estimated 42.1 million Americans were smokers.[3] Of these, about three-fourths were daily smokers, and about one-fourth intermittent smokers. Over time, the prevalence of smoking has declined, from a high of 42.7% in 1965 to the current level of 18%. The decrease in male smoking prevalence is even more dramatic, falling from a high of 54% in 1955 to the current level of 20.5%.[4] Smoking among women rose to a high of 34% in 1964, before its decline to the current level of 16%.[3]

It was initially hypothesized that quitting smoking would be easier for light and intermittent smokers, and

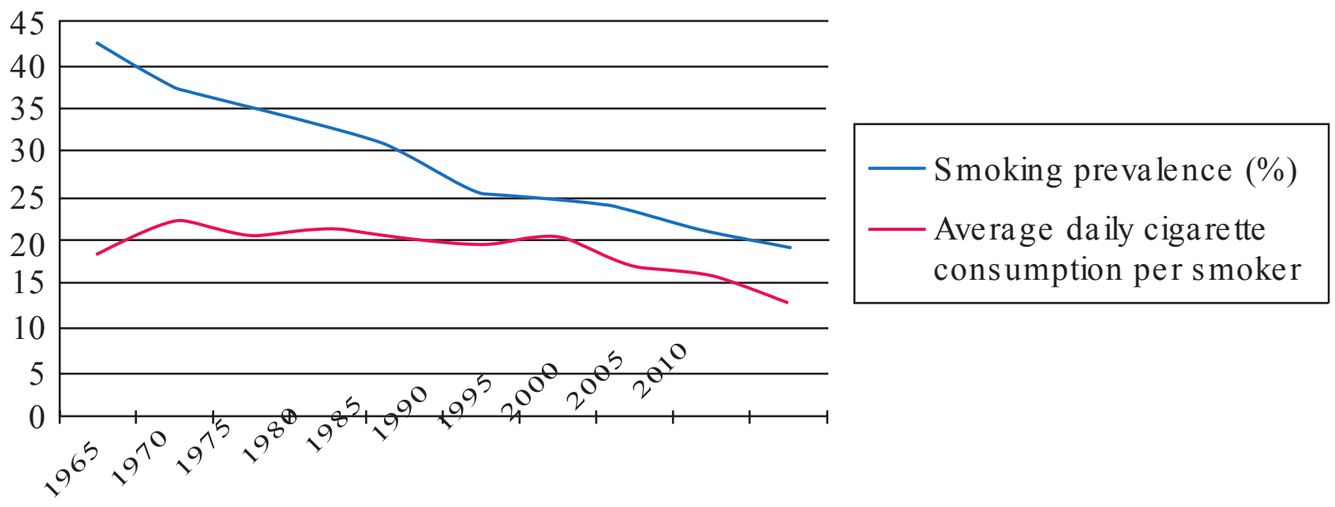


Figure 40-1. Smoking prevalence and average number of cigarettes smoked per day per current smoker, 1965–2010. (Adapted from Schroeder SA. How clinicians can help smokers to quit. JAMA 2012. 308(15):1586-1587.)[50]

thus as a result the remaining smokers would be more hardcore. But that has not turned out to be the case. Until 1995, smokers consumed, on average, 20 cigarettes daily. Beginning in 1995 that number began to fall, and today the average smoker smokes about 13 cigarettes per day, with about 22% of all smokers not smoking every day (Figure 40-1). Although 70% of smokers state that they would like to quit, only about 5% are able to do so, with the number being higher for those seeking medical assistance with quitting. For most smokers who want to quit, it takes as many as 10–12 attempts before they succeed.

RACIAL/ETHNIC MINORITIES

Differences in smoking prevalence exist among racial and ethnic groups, with Native Americans having the highest rate (31.5%), followed by whites (20.6%), African Americans (19.4%), Hispanics (12.9%), and Asians (9.9%). Substantial differences exist within these broad groups. For example, smoking rates among Americans of Korean descent are much higher than those of Filipino ancestry.[5] It may seem paradoxical that Asian-American men have relatively low smoking rates, since in their home countries (China, Korea, Japan, and Vietnam) male smoking rates exceed 50%. There is no evidence of selective immigration by nonsmoking Asian men, and studies have found that Asian immigrant smokers have high post-immigration cessation rates as a process of acculturating to a nation that stigmatizes smoking.

GENDER

In the period before World War II and up until the 1960s, men smoked at a much higher rate than women. Since then, the gap has narrowed but persisted. In 2012, men's smoking prevalence was 20%, compared with women's rate of 16%.[3] For youth, however, girls now have equal or higher smoking rates than boys.

PREGNANCY

A steady decline in smoking prevalence during pregnancy has followed the warnings that smoking is the most important contributor to premature delivery. However, only about one-third of women who stop smoking during pregnancy are still abstinent 1 year later. The highest rates of smoking during pregnancy occur among younger women, white or Native American women, and women of lower socioeconomic classes.

VULNERABLE POPULATIONS

Once a badge of sophistication, tobacco use is now disproportionately concentrated among marginalized populations. These include persons with mental illness, substance use disorders including alcohol and illicit drugs, incarcerated populations, the homeless population, and the LGBT community. As smoking has become stigmatized, it is also increasingly concentrated among those with low socioeconomic status. There are very high rates among those with General Educational Development (GED) diplomas, for example. Compared with the general population (18%), smoking prevalence rates among these groups are two to four times as high, despite the fact that the steep price of a pack of cigarettes exerts a substantial financial toll on many of these vulnerable persons. By contrast, the rate of smoking among US physicians is between 1% and 2%, among the lowest in the world.

LOW- AND MIDDLE-INCOME COUNTRIES

Smoking prevalence in low- and middle-income countries is generally higher than in developed nations, and much higher among men than among women. Rates are especially high among Asian men and the former Soviet Republics, including Russia, and relatively low among women in Africa, South East Asia, and most of Latin America, except for Chile and Paraguay. Although overall worldwide smoking prevalence decreased between 1980 and 2012 from 41% to 31% for men and from 11% to 6% for women, because of population growth the absolute numbers of smokers globally actually increased, from 718 million to 966 million. The highest rates of smoking for men include Russia and Indonesia (>50%) and for women Greece and Bulgaria (>30%).[6]

OTHER TYPES OF TOBACCO

Although cigarettes are the most common form of tobacco product used in the United States, a wide variety of other tobacco products exist. Non-cigarette forms of tobacco can be categorized into three groups: other combustible tobacco, smokeless forms of tobacco, and electronic nicotine delivery systems.[7]

COMBUSTIBLE TOBACCO

Cigars, pipes, water pipes, and roll-your-own tobacco comprise the major forms of other combustible tobacco used in the United States. Cigars contain shredded tobacco, wrapped in a tobacco leaf, and are produced as little cigars (manufactured and packaged as cigarettes), cigarillos, or large cigars. Pipes consist of a bowl that holds the tobacco, and an attached stem, where smoke is drawn, whereas water pipes (otherwise known as shisha, hookah, or narghile) use an indirect heating mechanism where smoke from the burned tobacco is passed through a container filled with water before reaching the user via a hose. Bidis and kreteks are made from loose-leaf tobacco, and are used frequently in other parts of the world including South Asia and South-East Asia, and among US immigrants from these regions. While the exclusive use of these products is low in the United States, dual use of cigarettes and other combustible tobacco products is common among youth, persons with low incomes, and those with low educational attainment.[8] The lower prices of these products compared to cigarettes, the wide variety of flavors, and the perception that these products are less harmful than cigarettes have contributed to the increase in the use of other combustible forms of tobacco.

SMOKELESS TOBACCO

Smokeless tobacco is a broad term for tobacco products that are used orally or nasally, and include chewing tobacco, snuff, snus, and newer dissolvable tobacco products. Chewing tobacco is sold as long strands of tobacco, which are chewed or placed in between the cheeks, gums, or teeth. The nicotine is absorbed through the tissues of the mouth, and the user spits out the tobacco after its use. Snuff and snus are finely ground tobacco that are sold in their dry or moist forms, and used in a manner similar to chewing tobacco, without the need for spitting. Other types of newer dissolvable tobacco products include tobacco lozenges or pellets or toothpick like strips, which are produced in a wide variety of flavorings that appeal to youth and young adult populations. Exclusive use of smokeless tobacco is more common among men than among women, and is highest among the young adult population (18–24 years) and those with less than a high school education. Dual use of cigarettes and smokeless tobacco is more prevalent among youth and young adults, those with low incomes, and low educational attainment.

ELECTRONIC NICOTINE DELIVERY SYSTEMS

Electronic nicotine delivery systems originated in China in 2006, and became available worldwide between 2008 and 2009. Otherwise known as e-cigarettes, these devices are constructed to resemble cigarettes, and deliver a vaporized solution of nicotine. They come in a wide variety of flavorings (e.g., licorice, chocolate, and strawberry), which appeal to youth and young adults. Consequently, use of e-cigarettes among the youth and young adult population has increased substantially in recent years. The prevalence of e-cigarette use doubled between 2011 and 2012 from 3.3% to 6.8% among youths in grades 6 through 12, and from 6.2% in 2011 to 3.3% in 2010 among adults.[9]

HEALTH CONSEQUENCES OF TOBACCO USE

TOBACCO USE

Tobacco use accounts for about 480,000 deaths annually in the United States and more than 5 million worldwide. An additional 8 million persons suffer from diseases caused by smoking in the United States alone. The list of diseases caused by tobacco use is large, and it continues to expand over time. For some illnesses, such as lung cancer, the risks are staggering. But all of the conditions listed in Table 40-1 are more likely to occur if a person uses tobacco, especially combustible tobacco.

SECONDHAND SMOKE

In addition to the health consequences of active smoking, inhalation of secondhand smoke is also dangerous, accounting for an estimated 50,000 of the annual 480,000 deaths in the United States. The major causes of death from secondhand smoke exposure are diseases of the cardiovascular and cerebrovascular systems. Persons with these conditions can be harmed from minimal exposure to passive smoking, because even very low exposure to cigarette smoke causes changes in platelet adhesiveness and arterial endothelial function. Secondhand smoke can also increase the odds of lung cancer, nasal sinus cancer, exacerbations of asthma and other respiratory conditions, and decreased hearing in teenagers. Reproductive and developmental problems from secondhand smoke exposure include premature delivery, low-birth-weight infants, sudden infant death syndrome, childhood depression, and childhood middle ear disease. In some states and communities, it is illegal to smoke in an automobile if children are present. Cigarette-induced fires cause burns, smoke

TABLE 40-1. Health Hazards of Smoking

Cancer	Cardiovascular	Pulmonary	Gastrointestinal
• Lung • Oral cavity and pharyngeal • Larynx • Nasal cavity, sinuses, and nasopharynx • Bladder and kidney • Cervix • Colon • Liver • Pancreas • Esophagus • Stomach • Acute myeloid leukemia • Prostate	• Coronary heart disease and acute MI • Cerebrovascular disease and stroke • Peripheral arterial disease/ impotence • Abdominal aortic aneurysm	• Lung cancer • Chronic bronchitis • Emphysema	• Peptic ulcer • Esophageal reflux • GI cancers

Infection	Other	Reproductive
• Tuberculosis • Worse recovery from pulmonary infections • Pneumococcal pneumonia • Legionnaires disease • Meningococcal disease • Periodontal disease • H. pylori • Influenza • HIV	• Type II DM • Early menopause • Osteoporosis • Cataract • Macular degeneration • Rheumatoid arthritis • Alzheimer disease • Poor surgical outcomes • Sleep disorders • Premature skin wrinkling • Altered drug metabolism	• Reduced fertility in women • Premature birth • Poor birth outcomes • Congenital anomalies, low birth weight • Abruptio placentae • Spontaneous abortion • Childhood obesity

inhalation damage, and death. Pediatricians have publicized the risk of thirdhand smoke exposure, which occurs when infants and young children orally ingest tobacco smoke residues that have accumulated on the clothes and furniture of smokers. These chemicals can exacerbate respiratory and middle ear infection and are potentially carcinogenic.

SMOKELESS TOBACCO AND OTHER ELECTRONIC NICOTINE DELIVERY SYSTEMS

Smokeless tobacco, while not as harmful as combustible products, also carries health risks, most notably oral and pharyngeal cancers, and also leukoplakia, gingivitis and gingival recession, poor recovery from oral surgery, and staining of teeth. Ingestion of tobacco products, including the nicotine found in electronic cigarettes, is an increasingly common cause of childhood poisoning. Data on the risks of using electronic cigarettes are emerging, as this product increases in popularity. The contents of e-cigarettes include propylene glycol, nicotine, nitrosamines and other known carcinogens, and ultrafine particles. While less harmful than combustible tobacco products, e-cigarettes have led to burns, explosions, and nicotine toxicity among children who ingest the contents of the cartridges.

Whether the e-cigarette is—on balance—helpful or harmful has stirred much debate in the tobacco control community. Opponents cite predatory marketing practices, packaging of the product in ways that appeal to youth, such as adding fruit or chocolate flavoring, the concern that e-cigarette usage will prove a gateway to combustible tobacco for youth, and that it will deter smoking cessation activities among established smokers. Others see the potential for great health benefit if smokers switch to e-cigarettes, which, although not proven to be safe, are likely safer than combustible tobacco. There is general consensus, however, around three points: there should be regulation of marketing practices so that the product is not marketed to youth; there should be no tolerance for e-cigarette vapor in public places; and we need to know more about the safety profile, the risk of serving as a gateway, and the potential for helping smokers quit. In April 2014, the Food and Drug Administration (FDA) issued a proposed rule that would extend to currently unregulated tobacco products including electronic cigarettes. Under the proposed rule, makers of these tobacco products would need to register with the FDA and report product ingredients, only market new tobacco products after FDA review, make direct and implied claims of reduced risk only after the FDA has confirmed scientific evidence, and not distribute free samples. In addition, makers of these products would be prohibited from selling their

products to underage youth and would need to include health warnings on packaging. The FDA is expected to make a decision on its proposed rule in the near future.

IMPACT ON THE HEALTH-CARE SYSTEM

According to the 2014 report of the Surgeon General on the Health Consequences of Smoking, annual smoking-attributable costs in the United States were about $300 billion, including about $150 billion for medical care, about $150 billion from lost productivity due to premature deaths, and close to $6 billion from lost productivity due to secondhand smoke exposure.[10]

BENEFITS OF QUITTING

No matter how old a smoker is, she will accrue health benefits from quitting compared to what would have happened had she continued to smoke. For example, a smoker who quits at ages 25–34 saves an estimated 10 years of life. Benefits from quitting in the 35–44 years age group are 9 years, in the 45–54 years age group 8 years, and in the 55–64 years age group 4 years. Even for smokers older than 65 years, the risk of getting lung cancer or cardiovascular disease declines after stopping smoking.[11] Return of function and reduction of risk following smoking cessation follow a predictable course. Within weeks to months, respiratory and circulatory function improves. By 1 year, the risk of coronary heart disease decreases to one half that of a continuing smoker and by 15 years the risk is at the level of never-smokers. For cerebrovascular disease, after 5 years, the risk is similar to never-smokers. Although the risk of lung cancer persists, by 10 years it is half that of a continuing smoker.

CHALLENGES TO MANAGING TOBACCO USE

NICOTINE ADDICTION

Nicotine is a naturally occurring alkaloid found in combustible and noncombustible forms of tobacco. It is highly addictive and induces physical dependence and tolerance in a manner similar to other illicit substances, such as cocaine or heroin. In the brain, nicotine binds to nicotinic acetylcholine receptors and triggers the activation of brain circuits that are involved in the reward system and habit formation. Chronic exposure to nicotine leads to widespread alterations in brain neurotransmission that sustains and promotes addiction. Smoking cessation disrupts these neuro-adaptations and leads to nicotine withdrawal. Symptoms of nicotine withdrawal such as depressed mood, insomnia, irritability, and anxiety act as potent deterrents to smoking cessation, and lead to maintenance of the smoking habit.

Nicotine dependence and the severity of nicotine withdrawal symptoms tend to be higher among persons with mental health disorders or substance use disorders; these individuals have higher rates of smoking than that of the general population. Many years of twin and adoption studies have demonstrated that nicotine dependence is a heritable trait. Genome-wide linkage and association studies have identified numerous genes (e.g., cholinergic nicotinic receptor subunit genes) associated with nicotine dependence that are located on chromosomes in close proximity to others linked with psychiatric illnesses such as schizophrenia or bipolar disorder.[12] These genetic factors are one of the many reasons for the increased severity of nicotine addiction among individuals with mental health and substance use disorders.

SOCIAL NORMS

The first reports on the harmful effects of secondhand smoke were published in the 1980s. In the United States, legislation to ban smoking in the workplace was passed in 1994 and enacted in 1998, with California being the first state to implement smoke-free policies in the workplace.[13] While the protection of nonsmokers was the primary intent of these policies, studies have shown that such policies are also associated with reduced prevalence of smoking and increased cessation among smokers.[14,15] Since the mid-1990s, there has been a gradual expansion of smoke-free policies into public places, hospitality establishments, and hospitals. Until recently, correctional facilities, psychiatric hospitals, substance use recovery programs, public housing, and homeless shelters—settings that serve populations that are disproportionately affected by tobacco use—had a culture permissive of smoking. However, with changing norms around smoking in favor of stricter smoking restrictions and to protect nonsmokers from exposure to secondhand smoke, correctional facilities,[16] psychiatric hospitals,[17] and public housing[18] have moved toward implementing indoor and outdoor smoke-free policies. Less is known about smoke-free policies in homeless shelters and substance use recovery programs. The absence of a consistent policy around smoking in facilities that serve marginalized populations reinforces the culture of tobacco use in these settings, and may contribute to the higher rates of tobacco use among these populations.

TOBACCO INDUSTRY MARKETING AND SOCIAL MEDIA

YOUTH

Television and movies promote tobacco use as a socially acceptable activity. Tobacco companies spend billions of dollars annually to market their products,[19,20] and these

marketing strategies are directed specifically toward youth and young adults, women, racial/ethnic minorities, and other vulnerable populations. The three most heavily advertised cigarette brands, Marlboro, Newport, and Camel, were the preferred brands of cigarettes smoked by adolescents and young adults between 2008 and 2011.[21] Indeed, studies have shown the causal association between exposure to tobacco industry advertising and initiation of cigarette smoking among adolescents.[22] Storefront cigarette advertising is more common in low-income communities, and these retail establishments are often situated within 1000 feet of a school.[23] The close proximity of these convenience stores to schools increases children's exposure to a wide variety of tobacco products, potentially leading to increased experimentation and sustained use.

WOMEN

The tobacco industry is estimated to spend more than $5 billion dollars annually in creating brands and marketing strategies that appeal to women.[24] Products such as Virginia Slims, for example, associated their cigarettes with independence, success, and sex appeal to create brand loyalty in young women in the 1970s. Low-income women have been particularly vulnerable to tobacco industry tactics.[25] Military wives; women belonging to racial/ethnic minorities who live in urban, inner-city areas; "discount-susceptible" older female smokers; and less educated white women have been targeted by the industry since the 1970s.[25] Some of the strategies used by the tobacco industry include distributing discount coupons with food stamps, discount offers at point of sale, developing new brands for low-income women, and promoting luxury images to low-income African-American women.[25]

RACIAL/ETHNIC MINORITIES

Racial/ethnic minorities have also been targeted heavily by the tobacco industry. Marketing to Latinos and American Indians/Alaskan Natives has included the advertising and the promotion of cigarette brands with names such as Rio, Dorado, and American Spirit. Tobacco industry advertising at the point of sale is most common among gas stations, convenience stores, liquor stores, and tobacco stores; the density of these retail establishments is much higher in communities inhabited by racial/ethnic minorities.[26] Communities that have a higher African/American population, people on public assistance, or people living below 150% of the federal poverty line are more likely to have advertisements featuring menthol brands of cigarettes.[27] The specific targeting of low-income racial/ethnic minorities in combination with the tobacco industry efforts in establishing relationships with leaders from these communities (e.g., by providing employment opportunities to community leaders from these minority groups) has significantly undermined tobacco control efforts in these populations.

VULNERABLE POPULATIONS

Other vulnerable populations that have been targeted by the tobacco industry include the homeless population and persons with mental health disorders. These populations have among the highest rates of smoking, and their extreme economic, psychological, and social vulnerability has made them particularly susceptible to tobacco industry marketing tactics. Capitalizing on these circumstances, the tobacco industry has marketed heavily to these "downscale clients" by direct-to-consumer marketing strategies such as donating free cigarettes to shelters or soup kitchens, by advertising "value" brands that appeal to "street people," and by promoting a positive image through advocacy and large-scale donations to organizations that serve these population.[28] As an example, R. J. Reynolds Tobacco Company developed a marketing campaign entitled, "Project SCUM (Subculture Urban Marketing)," which was intended to increase sales of Camel cigarettes to specific consumer populations in San Francisco (e.g., gay men and homeless persons). A review of tobacco industry documents illustrates that the rationale for targeting these populations was a belief that these individuals may be "more impressionable or susceptible to marketing/advertising … ." and an underlying knowledge that the incidence of tobacco and substance use was higher among these populations.[28] Such strategies have contributed to the very high rates of smoking observed in these populations.

REGULATORY CLIMATE

While tobacco industry marketing influences the diffusion and acceptance of tobacco products, the regulatory climate is another factor that governs uptake of tobacco products. Regulation of tobacco products includes counter-industry strategies employed by the FDA to control the manufacturing, advertising, marketing, and distribution of tobacco products to the public. The FDA's public health framework for tobacco regulation includes eight elements: understand regulated products; restrict product changes to protect public health; prohibit modified risk claims that state/imply reduce risk without evidence; restrict marketing and distribution to protect public health; decrease harms of tobacco products; ensure industry compliance with FDA regulation through

Box 40-1. Common Pitfalls

- Failing to ask about tobacco use in clinical encounters.
- Inadequate training about addressing smoking cessation in clinical encounters.
- Lack of knowledge about available community resources for tobacco cessation.
- Not encouraging the adoption of smoke-free homes.
- Not understanding how mental illness and substance use influence tobacco use and cessation.

education, inspections, and enforcement; educate the public about FDA's regulatory actions; and expand the science base of regulatory action and evaluation. Such measures taken by the FDA are expected to minimize the harms of tobacco use on a population level.[29]

CHALLENGES IN THE HEALTH-CARE SYSTEM

Despite the fact that smoking cessation treatments are available and equally efficacious for all populations, disparities exist in access to smoking cessation treatment (Box 40-1). More than 70% of smokers report a desire to quit, and smokers cite a physician's advice to quit as an important motivator for attempting to stop smoking.[30] The majority of smokers see at least one or more health professionals each year; however, most smokers are not asked about their smoking status, urged to quit, or offered effective assistance in quitting.[2] Persons who belong to racial/ethnic minorities and low socioeconomic status as well as individuals who are older, disabled, or have mental illness may be less likely to receive advice to quit smoking from health-care providers.[31-34]

Many health-care providers are unfamiliar with the available treatments for smoking, or their efficacy, administration, and side effects.[30] Many physicians harbor fears that they do not have enough time and their counseling will be ineffective.[35] Training is often lacking, further adding to the hopelessness of physicians in addressing smoking cessation in their clinics. This is particularly true of providers counseling adolescents, arguably the most important group to target for prevention efforts.[36] Even when a health-care provider is armed with adequate knowledge, conflicting priorities and time pressures make it extremely difficult to address tobacco use and cessation.

System-wide barriers include limited resources for smoking cessation (e.g., counseling and pharmacotherapy) among patients seeking care in safety-net settings, where a large majority of uninsured and underinsured patients seek care, and limited exposure to educational messages around smoking cessation. Compounding these health systems barriers is the fact that reimbursements for smoking cessation counseling is valued less than a procedure and is either not reimbursed or poorly reimbursed by many health payers.[37] This may act as a disincentive for some health-care providers to devote time to this important task. These patient, provider, and systems-related barriers significantly curb efforts in promoting widespread access to tobacco cessation resources for all smokers, and especially to those who are affected disproportionately by tobacco use.

STRATEGIES FOR MANAGING TOBACCO ABUSE

PRIMARY PREVENTION

The vast majority of smokers initiate tobacco use before the age of 18 years[30] Delaying the age when children first experiment with smoking can reduce the risk that they become regular smokers and increase their chances of quitting if they do become regular smokers. All adolescents should be asked about tobacco use among their peers as well as within their home environment. Risk factors for youth smoking include peer more than parental smoking, behavioral problems, poor school performance, low self-esteem, rebelliousness or risk-taking behaviors, depression, anxiety, lack of ability to resist influences to tobacco use, and living in families of lower socioeconomic status or single-parent homes.

Counseling and behavioral interventions used in adults are useful in adolescents. However, given their developmental stage, many teens do not respond to warnings about the long-term adverse health outcomes of tobacco use, but may respond to short-term effects such as halitosis, skin wrinkling, and erectile dysfunction. Messages pertaining to the dangers of secondhand smoke and the addiction potential of nicotine along with anti–tobacco industry messages are the most highly effective messages to use when trying to reach teen smokers.[38] Policies such as prohibiting sales to minors and high cigarette taxes are also very effective components of decreasing youth smoking.

TREATING TOBACCO DEPENDENCE

Screening

Asking and recording smoking status as another vital sign has been suggested as one method of assuring that smoking does not drop off providers' radar as a problem, so those who have relapsed will be discovered and assisted. Guidelines recommend that clinicians begin by using the five A's mnemonic to initiate a brief intervention in

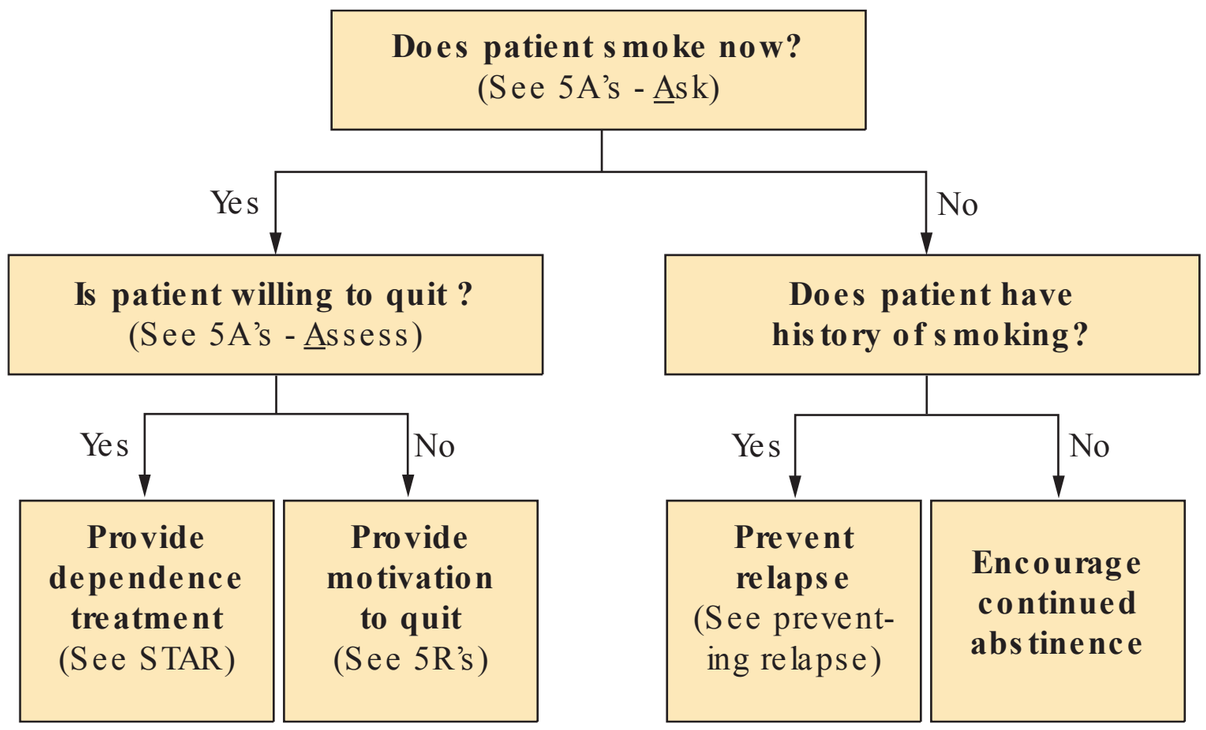


Figure 40-2. Algorithm for treating tobacco dependence.

every patient presenting to the clinical setting (Box 40-2; Figure 40-2).

Smoking Cessation

There is great variability in the addictive nature of smoking, in the number of daily cigarettes consumed, and in the ease of quitting for different people. Only about 4% of people quit spontaneously. Trials of counseling, coupled with pharmacotherapy, can produce higher rates (Figure 40-3), though it must be remembered that volunteers for smoking cessation drug trials are likely to be more motivated and thus more likely to quit, and the counseling provided in drug trials for both the active and placebo arms is likely to be more intensive and of higher quality than what exists in the real world. Thus, the smoking cessation results shown in the drug arms (16–28%) as well as in the placebo arms (8–12%) are likely higher than when counseling, with and without pharmacologic aids are used in real-world settings. A strong dose–response relationship between length of person-to-person contact and quit rates has been shown, and treatment delivered in four or more sessions has been shown to increase abstinence rates. Treatments delivered by multiple types of providers and in multiple types of formats are more effective than interventions by a single type of clinician in a single type of format.[30] Nevertheless, even brief interventions have been shown to have a significant benefit in helping patients quit smoking. Although daily costs of

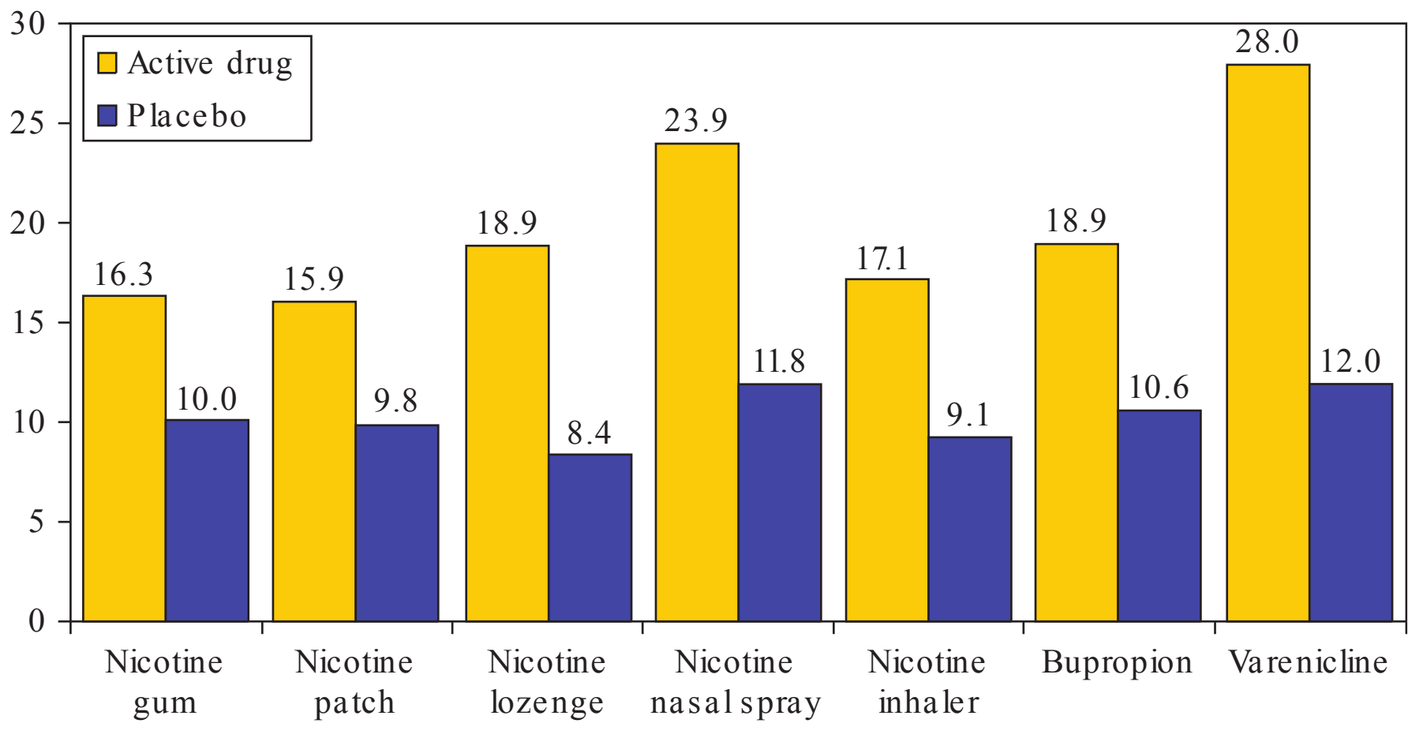


Figure 40-3. Long-term quit rates for available cessation medications. This chart summarizes the long-term (≥6 month) quit rates observed with the different nicotine replacement therapy products, bupropion SR, and varenicline based on data derived from 145 different randomized-controlled trials. It is not appropriate to compare the active medications with respect to clinical efficacy; however, the quit rates from each of the methods is approximately twice that of its corresponding placebo control treatment arm. (Data adapted from Cahill et al,[51] Stead et al,[52] and Hughes et al.[53]) (Adapted from "Rx for Change"—developed through a collaboration of the American Society for Anesthesiologists and the Rx for Change: Clinician-Assisted Tobacco Cessation Program. Funded by the National Cancer Institute and the Robert Wood Johnson Foundation.)

Box 40-2. The Five A's Mnemonic

Ask
- Screen patients for smoking at each and every visit. Consider making it a vital sign.

Advise
- Clearly advise patients to quit at every visit.
- Personalize the message: Tie tobacco use to a current health problem, its cost, or the impact on others.
- Stress total abstinence as the goal.

Assess
- Assess each smoker's willingness to quit at every visit.
- If willing, offer behavioral and pharmacologic treatment, including intensive treatment if available.
- If unwilling, provide a motivational intervention (see five R's).
- Provide information/resources tailored to the patient (adolescent, pregnant smoker, racial/ethnic minority).

Assist
- Assist patient in making a quit attempt (see STAR mnemonic).

Arrange
- Arrange follow-up tailored to the patient.

Box 40-3. STAR Mnemonic

Set a quit date.
- Set a quit date, ideally within 2 weeks.
- The goal is for total abstinence.

Tell family, friends, and coworkers.
- Elicit support by telling family, friends, and coworkers about the quit plan. Request understanding and support.
- Solidify resolve.

Anticipate challenges.
- Ask open-ended questions and discuss past quit attempts to elicit the triggers for smoking.
- Identify strategies to overcome triggers to smoking.
- Create a plan to prevent relapse and orchestrate support.
- Encourage housemates to quit with patient or not smoke in the patient's presence.
- Review nicotine withdrawal symptoms.
- Recommend abstention from alcohol during quit attempt.
- Recommend pharmacologic treatment.
- Encourage the patient to seek help before relapse.

Remove tobacco products.
- Before the quit date, get rid of all cigarettes and tobacco products.
- Avoid smoking in places where the smoker spends a lot of time (home/car/work).

Follow-up for quit attempt
- Follow-up 1 week after quit date.
- Follow-up 1 month after quit date.
- Phone interventions may be helpful.
- Congratulate successes.
- If relapse occurs, review circumstances and recommit to the quit process by setting a new quit date.
- Use the relapse as an opportunity to assure success.
- Review medication use and side effects.
- Consider referral to more intensive treatment.

pharmacotherapies are comparable to the cost of a pack of cigarettes, most vulnerable patients will have difficulty coming up with the price of a packet of the over-the-counter products or the cost of the prescription product. Thus, providing ways to pay for these products is essential.

Smokers' Willingness to Quit

When it is determined that a patient is ready to quit, the provider should help with a quit plan. The STAR mnemonic may be used to address all the major components to an effective quit plan (Box 40-3).

The Smoker Who Is Unwilling to Quit

Smokers may lack information about the harmful effects of tobacco because of poor health literacy or language barriers, or because no one has ever taken the time to tell them. Additionally, they may lack the required financial resources, may have concerns about quitting including fears of withdrawal symptoms, or may be demoralized because of previous relapse.

Disinterest in quitting or protest that smoking is enjoyable may mask a profound doubt in ability to overcome the habit. Reasons for continued smoking may be expressed in a number of ways, from indifference to anger. However, challenging this assumption prematurely may be met with resistance to quitting. Promoting motivation to quit is most likely to be successful when the clinician is empathic, promotes patient autonomy, avoids arguments, and supports the patient's self-efficacy by identifying previous success in behavior change efforts (Box 40-4) (see Chapter 12).

The Smoker Who Has Recently Quit: Preventing Relapse

Mr. Jones abstains from smoking for over 15 years and does well. However, when his daughter dies unexpectedly, he relapses and needs to be hospitalized for a COPD exacerbation. At first, he is ashamed of smoking again, but when he returns to facilitating the group, he discusses his relapse as predictable. His doctor does not ask about the smoking relapse as she assumes he no longer smokes, but when Mr. Jones brings up what happened, they decide to restart nicotine patches and bupropion.

Box 40-4. The Five R's

Relevance

- Encourage the patient to reflect on why quitting is personally relevant.
- Use reflective listening and open-ended questions.

Risks (Cons: see "Health Consequences of Tobacco Use" section)

- Ask the patient to identify the negative consequences of tobacco use.
- Highlight the risks that are most relevant to the patient.
- Discuss short-term, long-term, and environmental risks.

Rewards (see Pros and Cons in "Core Competency" section)

- Ask the patient to identify the benefits of smoking.
- Highlight the benefits that are most relevant to the patient. Discuss the pros of smoking for the patient.
- Add health benefits of quitting if the patient does not articulate these.

Roadblocks

- Ask the patient to identify barriers and impediments to quitting.
- Solve problem with the patient by noting elements of treatment that could address barriers.

Repetition

- Perform a motivational intervention at every encounter.
- If past failure is a concern, notify the patient that most people make repeated quit attempts before success.
- Stress relapse as an opportunity to plumb for success.
- Schedule follow-up.

Often in busy clinical practices, it is easy to assume that once the provider has successfully helped a smoker quit, smoking no longer needs to be addressed. However, it is essential to continue to address the issue of smoking with the patient to prevent relapse. Most relapses occur within the first 3 months after quitting, although some relapses occur months or even years after the quit date.[30] Consequently, follow-up through clinic visits and telephone calls is critical during the first 3 months. Encourage patients to report any difficulties promptly, including lapses, depression, and medication side effects while continuing efforts to quit. Congratulate the recovering smoker on success and encourage continued abstinence. Smokers respect the opinions of health-care providers and these short interventions are well received.

When to Intervene

Although providers should not wait for special circumstances to discuss smoking cessation, there may be times when a patient is more motivated to quit, such as at the onset of new medical symptoms, a hospitalization, a myocardial infarction, impending surgery, a friend recently diagnosed with lung cancer, pregnancy, the recent birth of a child, a new child at home, or diagnosis of asthma in a child. Tailoring any event to a patient's circumstances can be used as a motivating factor. For instance, smoking cessation before middle age is associated with a more than 90% reduction in tobacco-attributable cancer risk[39]; hence, the mid-life birthday of a patient is a perfect time to bring up quitting.

Pharmacotherapy

In addition to counseling, all smokers making a quit attempt should receive pharmacotherapy, except in the presence of special circumstances. Additionally, long-term smoking cessation pharmacotherapy can be considered as a strategy to reduce the likelihood of relapse. It is important to remember when choosing a pharmacotherapeutic regimen that patient preference and expectations regarding outcome are important. Seven first-line pharmacotherapies are approved by the FDA to be safe and effective for tobacco-dependence treatment: bupropion SR, varenicline, nicotine gum, nicotine patch, nicotine lozenge, nicotine nasal spray, and nicotine inhaler. See Table 40-2 for a summary of the dosing, recommended usage, cost, contraindications, side effects, and other notes.

Pregnancy

Use of pharmacotherapy is controversial during pregnancy, because none of the medications have been tested in pregnant women.[40] A number of studies have shown that nicotine presents risks to the fetus, including neurotoxicity. Treating a woman with nicotine replacement, however, may actually reduce the amount of nicotine she is absorbing if she is a heavy smoker and avoids exposing the fetus to the other toxic compounds found in smoke. Intermittently dosed nicotine products are probably safer in pregnancy than the patch, with its continuous release of nicotine. Thus, the ideal smoking cessation strategy for a pregnant woman would be intensive counseling. If that approach does not work, adding nicotine replacement, though not without theoretical risk, is preferable to continuing to smoke. Many pregnant smokers who quit during pregnancy resume smoking after delivery, thereby putting themselves and their infant at risk. Intensive smoking cessation efforts should continue after pregnancy is terminated.

Harm Reduction

In harm reduction strategies, tobacco users alter or decrease, rather than eliminate, their use of nicotine or tobacco. Although total abstinence from cigarettes is a goal, as increased health risks have been documented even in smokers who smoke less than five cigarettes per day,[41] there is evidence that reduction in smoking is helpful.

TABLE 40-2. Review of Clinical Use of Pharmacotherapies for Smoking Cessation[a]

Pharmacotherapy	Precautions, contraindications	Adverse effects	Dosage	Duration	Availability
First line Sustained release bupropion hydrochloride	History of seizure History of eating disorders	Insomnia Dry mouth Seizures	150 mg every morning for 3 days, then 150 mg twice daily (begin treatment 1–2 weeks pre-quit)	7–12 weeks Maintenance up to 6 months	Prescription only
Nicotine gum		Mouth soreness Dyspepsia	1–24 cigarettes/day; 2 mg gum (up to 24 pieces/day) ≥25 cigarettes/day; 4 mg gum (up to 24 pieces/day)	Up to 12 weeks	OTC only
Nicotine inhaler		Local irritation of mouth and throat	6–16 cartridges/day	Up to 6 months	Prescription only
Nicotine lozenge		Nausea/heartburn	Time to 1st cigarette >30 min: 2 mg lozenge Time to 1st cigarette ≤30 min: 4 mg lozenge Between 4 and 20 lozenges/day	Up to 12 weeks	OTC only
Nicotine nasal spray		Nasal irritation	8–40 doses/day	3–6 months	Prescription only
Nicotine patch		Local skin reaction Insomnia	Ex. 21 mg/24 h 14 mg/24 h 7 mg/24 h Ex. 15 mg/16 h	4 weeks Then 2 weeks Then 2 weeks 8 weeks	Prescription and OTC
Varenicline	Significant kidney disease Patients on dialysis Severe psychiatric disease	Nausea/trouble sleeping Abnormal or vivid/strange dreams Depressed mood and other psychiatric symptoms	0.5 mg/day for 3 days 0.5 mg twice/day for 4 days Then, 1 mg twice/day (Begin treatment one week pre-quit)	3–6 months	Prescription only

Abbreviation: OTC, over the counter.
[a]The information contained in this table describes the prescribing instructions for the seven FDA-approved first-line medications. This information is not comprehensive. See package inserts for additional information, including safety information.
Source: Adapted from Clinical Practice Guideline Treating Tobacco Use and Dependence 2008 Update Panel, Liaisons, and Staff. A clinical practice guideline for treating tobacco use and dependence: 2008 update. A U.S. Public Health Service report. Am J Prev Med. 2008;35(2):158-176.[40]

Patients who reduce smoking may eventually quit,[42] and in the meantime asthma symptoms,[43] worsening lung function, and risk of lung cancer have all been shown to decrease.[39] Shifting to low-tar and low-nicotine cigarettes show no reduction in risk because smokers compensate by increasing the frequency or depth of inhalation per cigarette.[44] Switching to smokeless tobacco products or electronic nicotine delivery devices in order to facilitate cessation has not been shown to increase smoking cessation rates on a population level.[45]

SYSTEM-BASED APPROACHES TO SMOKING CESSATION

System-based approaches—referral to telephone quit lines or smoking cessation specialists or group classes to help patients quit smoking—are most useful. Creating smoking cessation consult services; implementing systematic screening and tobacco-user identification systems; and ensuring adequate training in smoking cessation for personnel and availability of appropriate resources are important interventions. Health-care facility chart audits, electronic medical records, and computerized patient databases can be used to evaluate the degree to which health-care providers are identifying, documenting, and treating smokers. Feedback can be provided to providers in the form of "report cards" to remind providers about the importance of addressing tobacco use in their practices. Guaranteeing that pharmacotherapies are covered or provided for patients at minimal cost is particularly important.

Finally, reimbursement for tobacco cessation programs is essential. Insurers and purchasers of insurance must make certain that all insurance plans include a reimbursement benefit for smoking cessation counseling and pharmacotherapy as well as a reimbursement for clinicians providing tobacco-dependence treatment. The Affordable Care Act provides for reimbursement of all US Preventive Service Task Force–recommended treatments, including smoking cessation counseling and pharmacotherapy.

TELEPHONE QUITLINES

Toll-free telephone quitlines connect smokers with trained counselors who take an individual smoking history, prepare a customized cessation plan that includes pharmacotherapy, and provide follow-up telephone calls to assess progress. Access to toll-free telephone quitlines is available in all states.[1] The Department of Health and Human Services has a national number (1-800-QUIT-NOW) that forwards callers to services in their area. In many states, clinicians can directly fax referral forms from their offices or from the hospital, so that the state quitline can proactively contact the smoker.

Telephone counseling is effective in promoting cessation. In a large, randomized controlled trial of more than 3000 patients, telephone counseling through the California state quitline (1-800-NOBUTTS) nearly doubled abstinence rates.[46] Many smokers who call the telephone quitline suffer from major depression, suggesting a need for targeted interventions for this population. Telephone quitlines offer convenience, the ability to serve diverse and multilingual populations, and anonymity. The majority of patients also prefer using quitlines to clinic visits.[1] Internet programs to help people quit smoking are a newer variation on telephone counseling, and evidence is emerging that they are effective.

POLICY-BASED APPROACHES TO SMOKING CESSATION

As health-care providers and patient advocates, providers have the opportunity to take part in many community-based and broader initiatives to combat the epidemic of tobacco in the United States. Many of these policy-based initiatives have been shown to be more effective in tobacco cessation than any clinic-based intervention practitioners can provide. Therefore, it is useful to review some of these policy-based initiatives.

Primary Prevention and Policy-Based Approaches in Children

Primary prevention of smoking in US youth is the focus of many legislative and programmatic interventions. Effective legislative methods useful in decreasing initiation of smoking among youth include use of federal, state, and local excise taxes to increase the cost of cigarettes, restricting tobacco advertising and promotional activities (including bans on point of purchase and print advertising as well as sponsorship of events by tobacco companies), mandating tobacco education in schools, banning representation of smoking on television, giving films with smoking an R rating, and making tobacco access laws for minors more strict (including requirements to keep tobacco products behind the counter and bans on cigarette vending machines). CVS pharmacy has recently announced that it will no longer sell tobacco products, and other chain pharmacies may follow CVS's lead.[47] Antismoking media campaigns and counter-advertising, merchant education and training, school-based tobacco use prevention programs that help model for children the identification and resistance of social influences that lead to smoking, and bans on smoking on school grounds have all been shown to be effective. Restrictions on indoor smoking, campaigns to discourage family and friends from providing cigarettes to youth, and promoting smoke-free homes also work.[48] Evidence supports the use of multiple modalities in combination with a comprehensive program against tobacco use and initiation. The prevalence of smoking among youth has declined most rapidly in states that have used the most extensive paid media campaigns in combination with other antitobacco activities in their comprehensive antitobacco campaigns.[48]

Policy-Based Approaches to Smoking Cessation in Adults

Policy-based interventions used to decrease smoking in adults are also important interventions. In addition to the policies described in the preceding section, such as tobacco excise taxes, tobacco-free work places are an example of an effective policy-based intervention in adults. In addition to protecting both workers and patrons from secondhand smoke exposure, smoke-free workplace policies are associated with decreased cigarette consumption and possibly with increased cessation rates among workers and members of the general public. These measures are supported by the general public and do not decrease business revenues in restaurants and bars.[49] Smoke-free homes, another policy-based approach, not only reduce exposure to secondhand smoke but also promote cessation among smokers.[14] Smoke-free homes have been shown to be associated with increased successful quit attempts among smokers, increased efficacy of pharmaceutical aids for cessation, and reduced relapse to smoking.

Language-appropriate, culturally competent, targeted education campaigns are being waged to combat tobacco company advertising and promotional activities in minority and low socioeconomic status populations. Continued monitoring of tobacco industry attempts to target these populations is necessary to develop a comprehensive understanding of the influences that encourage individuals in these high-risk populations to smoke and design effective counter-marketing campaigns.

CONCLUSION

Tobacco use is a scourge on health. Although cigarette-smoking rates have declined in the past three decades, the rate of decline has slowed in the recent years. Among

vulnerable populations, cigarette-smoking rates remain very high. Without efforts to increase access to cessation aids for vulnerable populations, the rate of smoking among the general population may not decline to the goal set by the Healthy People 2020. Tobacco use has also evolved to include a range of novel products, which have been marketed heavily to youth and vulnerable populations. Whether these products result in a net public health benefit by increasing cessation rates remains unknown. However, the potential for augmenting addiction by promoting dual and poly-use is a concern, and poses a risk to current population-wide efforts to reduce tobacco use. Helping current smokers quit and keeping people, particularly young people, from starting should be top priorities for all health professionals. Achieving these goals will require a spectrum of responses from efforts of individual providers, clinics, hospitals, and health-care systems to antismoking media campaigns, and legislative restrictions on promotion and sale of tobacco products and smoking in public places.

- Smoking is the leading cause of preventable death in the United States.
- The poor, the mentally ill, and those with substance use disorders bear the brunt of poor health caused by cigarette smoking.
- Primary prevention in the young is best tackled through comprehensive public policies and medical counseling of children, teens, and their parents.
- All health professionals should address smoking cessation at every opportunity.
- Systems-based interventions are essential to support tobacco cessation efforts.
- Public policies and regulations are needed to combat the powerful and pervasive promotion of tobacco products by cigarette companies.

Practical Smoking Cessation Tips and Exercises

General approach

- Avoid "shoulds." Use alternatives, such as, "Consider becoming smoke free."
- Be empathetic and respectful about the difficulty of quitting.
  - —Remember: Shame about smoking may actually inhibit cessation.
  - —Acknowledge smoking as an addiction, not a filthy habit or deficit in the person.
  - —Fear-based motivation may cause feelings of powerlessness and hopeless.
  - —Fear may break a person out of denial, but as a constant motivational tool is often counterproductive.
  - —Desire-based motivation can be more powerful than avoidance.
  - —Smoking cessation takes time and is a process. Do not get discouraged.

Exercises

Awareness

- Ask patients to pay attention to how they feel when inhaling the cigarette.
- Rate the four components of addiction to cigarettes on a scale of 1 to 5 in importance:
  - —Nicotine (although remember that nicotine effects and psychological reasons for smoking may be intertwined and impossible to distinguish)
  - —Hand and mouth stimulation
  - —Psychological and emotional impulses for smoking
  - —Review conditioned cues: smoking after meals, during break times, when angry or upset, etc.
- Use this information to focus interventions such as stress management.

Deep breathing

- Deep breathing can help manage stress and eliminate cigarettes.

  Deep breathing instruction: Purse lips and exhale as though blowing out a candle. Keep blowing until you can no longer exhale, and then allow a natural inhalation. The inhalation will be deep and go to the abdomen. Practice a minimum of three times daily with 5–10 deep breaths each time. Use this to postpone or eliminate cigarettes.

Delaying

- Cut drinking straws into the length of a cigarette. Put several into your cigarette pack. When you pull up a straw, deep breathe instead of smoke.

Pros and Cons

- Reviewing an individual's reasons for smoking provides the basis for exploring new responses to important needs. For example:
  - —Smoking helps a woman establish boundaries with men. She can use the lit cigarette to indicate "don't come closer than this."
  - —Smoking gives a person a reason to go outside and take a break from being with people, especially if he or she tends to be shy.
  - —Smoking lets you feel cool and rebellious.
  - —Smoking helps keep you awake, relaxed, and calm, and controls anger, hunger, and loneliness.
- Desire-based motivation: List the cons about smoking. Turn the cons into the pros about being smoke free. For example, feeling like a bad mother and nurse because of smoking can be turned into, "I am devoted to my children and health and can be fearless and proud and smoke free."

DISCUSSION QUESTIONS

1. Why do you think that health-care professionals in your field do not tackle smoking cessation as frequently as they should? What strategies could you use in your setting to improve smoking cessation efforts?
2. Discuss ways in which novel tobacco products may change current patterns of tobacco use. Discuss how the regulation of these products might affect patterns of tobacco use.
3. Some argue that without the production and sale of tobacco, our economy would suffer tremendously and that public policies to restrict tobacco use hurt the economy. Discuss.
4. Practice and role-play with your neighbor using the five A's, five R's, and STAR techniques.
5. Compare and contrast the health benefits of quitting smoking with other treatments that are often prescribed.

RESOURCES

Smoking cessation leadership site: http://smokingcessationleadership.ucsf.edu.

Smoking cessation leadership site provides information on research on tobacco use and cessation, information on tobacco use among persons with mental health and substance use disorders, resources for healthcare providers and smokers on smoking cessation, webinars, and other tools for smoking cessation.

http://www.cdc-gov/tobacco/

http://www.ahrq.gov/

Many hospitals have smoking cessation services available that enable referral of smokers as necessary. Many states have toll free quit lines (e.g., in California, 1-800-NO-BUTTS), and the national number (1-800-QUITNOW) forwards callers to services in their area.

Comprehensive information from patient aides to clinical recommendations to information on how to develop or fund comprehensive tobacco programs are available on the Centers for Disease Control and Prevention and the Agency for Health Care Research and Quality Web sites.

Internet-based programs such as QuitNet can provide online chat rooms and can give smokers with access to a computer a sense of community with other smokers. If patients do not have their own computer, the public library is a smoke free environment in which they can access computers. http://www.quitnet.com.

The American Lung Association has significant information and an online program called "Seven Steps to a Smoke-Free Life" to which patients can be referred. http://www.lungusa.org/tobacco.

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Chapter 41

Dental Care: The Forgotten Need

Francisco Ramos-Gomez, DDS, MS, MPH, Carolyn Brown, DDS, and Susan Fisher-Owens, MD, MPH

Objectives

- Review the importance of dental health through the life course.
- Describe the epidemiology of dental disease in vulnerable populations.
- Identify interventions to assure dental health in underserved communities.
- Discuss the importance of interprofessional education.

INTRODUCTION

The preservation of complete natural dentition is critical at all ages. In children, the prevention of early cavities is not only important for the healthy development of permanent teeth but also contributes to overall development and quality of life. The loss of teeth can bring negative social stigma, especially when tooth loss occurs at a young age. In addition to the social isolation and psychological pain that these problems can bring, general health may suffer as well.

People with poor dental health may have increased difficulty speaking, chewing, and swallowing, and in extreme cases, nutrition may be compromised. In patients with partial or complete dentures, chewing is difficult and in no way compares with natural dentition. Poor dentition also may lead to recurrent systemic infections such as pneumonia or endocarditis. Other conditions, such as worsening diabetes, cardiovascular disease, and preterm birth, may be exacerbated or increased by poor dental health (Box 41-1).

Factors influencing an individual's oral health begin before birth, with the oral and overall health of the mother; these influences persist throughout childhood and into adulthood. Thus, when assessing risk, one must consider the health of the child within the context of individual, family, and community influences (Figure 41-1). We all have intrinsic characteristics, but children are

Box 41-1. Major Findings of the Surgeon General's Report on Oral Health

- Oral diseases and disorders in and of themselves affect health and well-being throughout life.
- Safe and effective measures exist to prevent the most common dental diseases, dental caries, and periodontal diseases.
- Lifestyle behaviors that affect general health, such as tobacco use, excessive alcohol use, and poor dietary choices, affect oral and craniofacial health as well.
- There are profound and consequential oral health disparities within the US population.
- More information is needed to improve America's oral health and eliminate health disparities.
- The mouth reflects general health and well-being.
- Oral diseases and conditions are associated with other health problems.
- Scientific research is key to further reduction in the burden of diseases and disorders that affect the face, mouth, and teeth.

Source: From US Department of Health and Human Services. Oral Health in America: A Report of the Surgeon General. Rockville, MD: US Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.

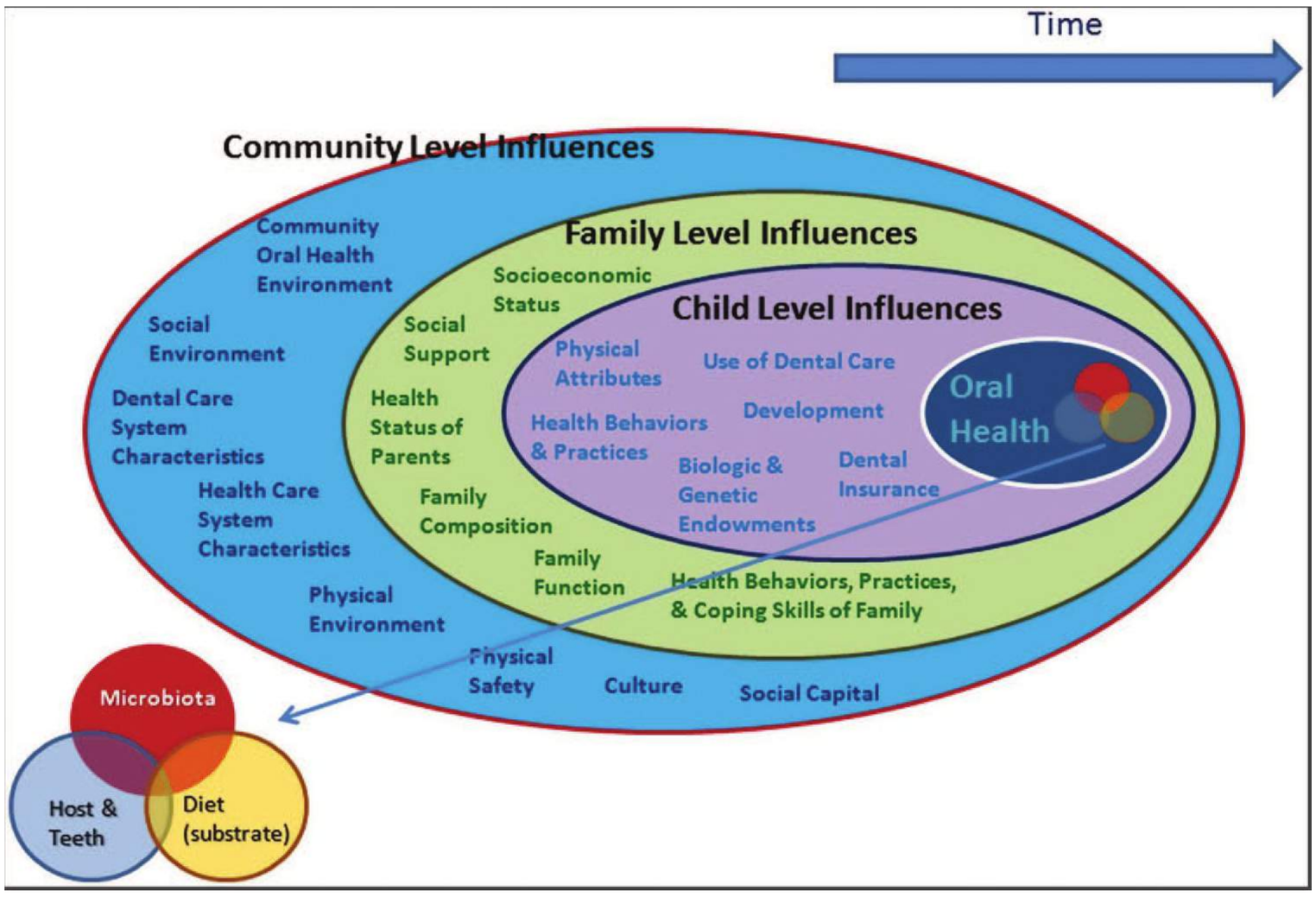


Figure 41-1. Child, family, and community influences on oral health outcomes of children. (From Fisher-Owens SA, Gansky SA, Platt LJ, et al. Influences on children's oral health: A conceptual model. Pediatrics 2007;120:e510-e520.)

greatly influenced by the families into which they were born. These families exist within communities, which exert both positive and negative social norms and physical options. These communities also are impelled by state and national policies. For children particularly, the passage of time can have great impact on their disease (or health) state and their resources to deal with it. These influences are numerous, but can be grouped broadly into five key domains: genetic and biological factors, social environment, physical environment, health behaviors, and utilization of dental/medical care.[1] Dental treatment strategies should reflect such factors. This chapter discusses the importance of dental health to general health throughout the lifespan, identifies risk factors associated with dental caries (cavities) and periodontal disease, and suggests methods of educating patients about oral health.

EPIDEMIOLOGY: WHO IS AT RISK?

Oral care is a vital part of providing comprehensive care to all patients. However, the relationship of oral health to the overall health of patients is often overlooked, and many nondental health-care providers do not incorporate dental health into their care. Many patients and providers have limited knowledge as to how to prevent dental illness, and most patients seek help only for acute dental problems.

Factors such as age, economic status, limited access to dental care, low education and literacy, the existence of mental or physical handicaps, and ethnicity all contribute to risk for dental caries (Figure 41-2) and periodontal disease (Figure 41-3). In addition, chronic illnesses, poor nutritional and lifestyle habits, and a lack of dental knowledge put many patients at risk not only for the loss of teeth but also for the degradation of their overall health and quality of life. Consequently, what amounts to "a silent epidemic" of oral diseases is affecting the most vulnerable citizens: poor children, the elderly, those with disabling and chronic diseases, and many members of racial and ethnic minority groups.[2]

PREVALENCE OF ORAL DISEASE IN CHILDREN

The prevalence of dental caries is widespread around the world and in the United States, and can be classified as a communicable disease.[3] Tooth decay is the most chronic infectious, transmissible, and preventable childhood disease, with nearly 20% incidence of caries in children ages 2 to 4 years. In fact, in children, caries is five times more common than asthma and seven times more prevalent than



Figure 41-2. Severe early childhood caries.

CARIES RISK ASSESSMENT FORM FOR AGES 0 TO 5 YRS OLD

Patient Name:_____ **I.D.#**_____ **Age:**_____

Date:_____ **Assessment Date:** _____

NOTE: Any one YES in Column 1 signifies likely "High Risk" and an indication for bacteria tests	YES = CIRCLE 1	2	3	Comments:
1. Risk Factors (Biological Predisposing Factors)				
(a) Mother/caregiver has active dental decay in past year	YES			
(b) Bottle with fluid other than water, plain milk and/or formula		YES		Type(s):
(c) Continual bottle use		YES		
(d) Child sleeps with a bottle, or nurses on demand		YES		
(e) Frequent (> 3 times/day) between-meal snacks of sugars/cooked starch/sugared beverages		YES		# times/day: Type(s):
(f) Saliva-Reducing factors are present, including: 1. medications (e.g., asthma [albuterol] or hyperactivity) 2. medical (cancer treatment) or genetic factors		YES		
(g) Child has Special Health Care Needs		YES		
(h) Parent and/or caregiver has low SES (Socio-economic status) and/or low health literacy, WIC/Early Head Start		YES		
2. Protective Factors				
(a) Child lives in a fluoridated community (note zip code)			YES	Zip Code:
(b) Takes fluoride supplements			YES	
(c) Child drinks fluoridated water (e.g., tap water)			YES	
(d) Teeth brushed with fluoride toothpaste at least 2x daily			YES	# times/day:
(e) Fluoride varnish in last 6 months			YES	
(f) Mother/caregiver understands use of xylitol gum/lozenges			YES	
(g) Child is given xylitol (recommended wipes, spray, gel)			YES	
3. Disease Indicators - Clinical Examination of Child				
(a) Obvious white spots, decalcifications, or decay present on the child's teeth	YES			
(b) Existing restorations	YES			
(c) Plaque is obvious on the teeth and/or gums bleed easily		YES		
(d) Visually inadequate saliva flow		YES		
(e) New remineralization since last visit (List teeth):			YES	Teeth:

Child's Overall Caries Risk (circle): HIGH MODERATE LOW

Child: Bacteria/Saliva Test Results:	MS:	LB:	Flow Rate:	ml/min:	Date:
Caregiver: Bacteria/Saliva Test Results:	MS:	LB:	Flow Rate:	ml/min:	Date:

Self-management goals:

1. _____
2. _____

Since Last Visit:

New Cavitation: Y / N
New White Spot Lesions: Y / N
Dental Pain: Y / N
Referral Type: O.R. I.V. Oral Sedation

Clinician's Signature: _____ **Date:** _____ (Updated: 8/19/14)

Figure 41-3. Caries Management by Risk Assessment (CAMBRA).

hay fever.[2] By the age of 17, nearly 80% of the US population has had a cavity or filling. More than two-thirds of adults between the ages of 35 and 44 have lost at least one permanent tooth.[2] It is critical to prevent disease early in the primary dentition. Healthy baby teeth assist in the development of the permanent dentition, with implications for the proper placement of permanent teeth, speech, mastication of food and nourishment, self-esteem, and school readiness.

SOCIOECONOMIC STATUS AND THE UNINSURED

> Juana is a 33-year-old immigrant from Mexico. She has no insurance and few economic resources. She took time off from her work as a nanny to come to the dental office. She speaks only Spanish, and says she seeks medical care only when something hurts.

Despite overall improvements in oral health status in the United States, profound disparities remain in some population groups as classified by sex, income, age, and race/ethnicity. Many people do not access dental care because of financial barriers. In fact, Juana's practice of seeking dental care on an emergency-only basis has been shaped by her experience of inaccessibility, and is representative of many who live below the poverty line in the United States.

The prevalence of oral disease is significantly higher in those living below the federal poverty line. Poor children are twice as likely to have dental caries when compared with those from an affluent background. Moreover, they may exhibit behaviors that undermine oral health, such as increased juice consumption. The elderly population living in poverty is more likely to be edentulous.[2] An individual's environment, such as access to clean and optimally fluoridated drinking water, or fresh fruits and vegetables, also contributes to oral and overall health.

More than 108 million Americans lack dental insurance, 2.5 times more than those lacking medical insurance.[2] Additionally, the likelihood of seeking dental care is 2.5 times greater in children with dental coverage than in those without it.[2] Specific to Latinos, 76% of participants with dental insurance used services, compared with 47% of those without coverage.[4] In a study of Latino immigrants in Southern California, nearly 70% had no dental insurance, and Latino children were the least likely to have dental insurance coverage.[5]

Low-income patients seeking dental care (often only when a patient is in pain) often seek the cheapest alternative for treatment. In the case of a toothache, this may be extraction, even though the tooth could be treated and maintained in the mouth by other therapeutic and more expensive treatment. In many states, access to dental care for low income is often limited to the dental safety net, hospital emergency rooms, dental or hygiene schools, free clinics, or public health/federally funded dental clinics. Often, these programs have a higher demand for dental services than can be supplied.[6]

RACE/ETHNICITY

> Juana saw a dentist 5 weeks ago, but became frustrated in attempting to communicate with a non–Spanish-speaking provider. Since her last visit, she has had a swelling next to her lower right molar. She says the swelling comes and goes, as does the pain, but recently it has worsened. Although she knows she needs dental attention, she's discouraged because of the language/cultural barrier.

Many minority patients have great difficulty accessing dental care. In addition to financial constraints, language barriers, fear of jeopardizing immigration status, and the lack of minority providers may be deterrent factors to seeking care.[7] The Centers for Disease Control and Prevention outlines profound oral health disparities in non-Hispanic blacks, American Indians/Alaska Natives, and Hispanics.[8] Non-Hispanic blacks and Mexican Americans, aged 35–44 years, are nearly twice as likely to experience untreated tooth decay as non-Hispanic whites.

The presence of dental disease is rampant among Hispanic youth. Many studies reveal that Latino children are at particular risk for early childhood caries (ECC). Of those living below the federal poverty line, Mexican-American children were significantly more likely to have untreated caries when compared with non-Hispanic whites and non-Hispanic blacks. In those aged 2–4 and 6–8, Mexican Americans have the highest number of decayed and filled surfaces in primary dentition. In a study of young children near the California–Mexico border, 68% had ECC.[9] The prevalence of ECC in Latino children is likely a result, at least in part, of a lack of dental education and awareness within Hispanic communities.

INDIVIDUALS WITH PHYSICAL OR MENTAL BARRIERS

> Juana has diabetes. A review of her medical history reveals a family history of diabetes and early tooth loss. Her mother was a diabetic and died at the age of 48. Juana complains that her molar on the lower right is loose and wants to have it pulled. This is the fourth tooth she has had extracted in the past year. Juana is not aware that her loss of her teeth is related to her uncontrolled diabetes and poor oral hygiene.

Positive association has been established between several illnesses and periodontal disease, a chronic inflammatory disease of the soft tissues and bone, with conditions including preterm low birth weight,[10] hepatitis C, cardiovascular disease,[11] stroke, and emphysema.[12] A link

between diseases that affect the immune system, such as rheumatoid arthritis, Sjögren syndrome, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), and diabetes and periodontal disease has been well established.[13,14]

Observational studies have linked glycemic control in diabetics to the prevalence of periodontal disease. As diabetic control worsens, the likelihood of progressive periodontal disease increases. Current theory suggests a bidirectional relationship between diabetes and periodontal disease; control of periodontal disease helps control diabetes and vice versa.[14] Health-care providers caring for diabetics must include dental care in their comprehensive care plans. Some have referred to the dental extractions commonly seen in diabetics as another kind of "amputation" that providers should seek to prevent.

Adults and children with medical disabilities, chronic illnesses, or those considered "special needs" with medically complex conditions or the frail elderly have significant issues in accessing care, including travel to a dentist's office, appointment length, or difficulty finding oral health providers with special training and the physical setup necessary to treat a special needs patient. Similarly, individuals living in nursing facilities or chronic care homes may have limited options in accessing dental care. While some programs may arrange for in-house calls for oral health care, the scope of services may be limited and may or may not require patient financial obligation.

Quadriplegic patients and patients with physically impairing conditions such as Parkinson disease, multiple sclerosis, and stroke are likely to have more difficulty with brushing and flossing. Patients with severe mental disease are 3.4 times more likely than the general population to suffer loss of all their teeth.[15] This is due, in part, to lack of proper oral self-care, and by side effects of psychotropic medications, such as dry mouth. The mentally impaired, such as those with Down syndrome and autism, may rely solely on their caretakers for oral care. In some cases, access to care is difficult because many dental offices are unequipped to manage patients with these physical and mental conditions. In some cases, these patients must be admitted to a hospital and placed under general anesthesia to administer care.

LIFE COURSE THEORY

The life course theory (LCT) is a conceptual framework that seeks to encompass patterns for health and disease among populations in the context of structural, social, and cultural influences.[16] LCT places particular emphasis on the prenatal period, early childhood, and young adulthood as critical periods: times of "early programming." For instance, the overall health, environmental exposures, and experiences of the mother prior to conception or delivery can result in the disease or susceptibility of the child. Here we discuss many of the specific oral health–related risks associated with various LCT stages.

PERINATAL ORAL HEALTH

Over the last two decades in the United States, there has been much attention to the oral disease status of the mother during pregnancy as a possible contributor to negative birth outcomes such as gestational diabetes, preeclampsia, spontaneous preterm birth, low birth weight, or even fetal loss.[17-19] Boggess and colleagues summarize a two- to sevenfold increase in risk of adverse outcomes with concurrent active periodontal infection.[20]

Researchers at the University of North Carolina induced periodontitis in pregnant rodents[21] and found that the maternal infection, resulting from the colonization of and destruction by gram-negative anaerobes, leads to maternal systemic response of elevated inflammatory markers (mainly prostaglandins, tumor necrosis factors, interleukins, and C-reactive protein) and, perhaps, even preterm birth.[22,23] However, LCT challenges us to look even further downstream and determine how the child's health and development trajectory, and perhaps increased susceptibility to oral diseases later in life, is affected by exposure to these negative conditions resulting from the mother's periodontal infection.

Given the high incidence of chronic dental diseases, such as dental caries and periodontitis (a chronic inflammatory disease of the mouth), among US women of child-bearing age, it is critical to determine ways to minimize the negative impact on maternal and fetal responses to maternal periodontitis or gingivitis,[24] and to delay or decrease the likelihood or severity of colonization by dental caries–causing bacteria passed from mother to child.

Many organizations have held consensus conferences and meetings to address possible interventions. Most recently, American College of Obstetricians and Gynecologists has recommended a dental screening at the first prenatal visit, to increase the likelihood of early intervention.[25] The National Maternal and Child Oral Health Resource Center,[26] California Dental Association,[27] State of New York,[22] and other groups have identified interventions and oral health roles for dentists, obstetricians, allied health-care workers, and lay health workers to underscore the need for counseling pregnant women as early as possible about vertical transmission of caries and the maternal burden of disease from periodontitis. The importance of good oral health of both mother and their children is consistently outlined including breastfeeding, oral hygiene, and dental care utilization practices.

INFANT AND CHILD ORAL HEALTH

Infancy is generally a time of relative health, with great parental investment in preserving that health. Bottle feeding increases rates of Candida (thrush) in the mouth, and

later of caries development, so providers and health-care systems should encourage breastfeeding by the mother. In addition, infants' mouths are free of cariogenic bacteria, but this bacteria can be introduced when parents/caregivers with a high bacterial load prechew food, "clean" a pacifier in their mouth, or allow babies to stick their fingers in someone else's mouth before putting them back in their own. To delay or halt colonization of cariogenic bacteria, start with wiping the gums and then brushing teeth after eruption can set an infant onto a more favorable health trajectory.

ECC, also known as baby bottle tooth decay, is defined as a condition of demineralization of the enamel with different degrees of cavitation in the primary dentition of children younger than 6 years.[28] ECC, the most common chronic infectious disease in young children, is caused by bacteria, predominantly mutants, streptococci, and lactobacilli, which metabolize simple sugars to produce acid that demineralizes enamel, resulting in cavities. These bacteria are passed easily from mother to child, and consequently may develop as soon as teeth erupt.[9]

Children from ethnic minorities, those of low socioeconomic status or with limited access to dental services, are especially at risk for ECC (Figure 41-4). When left untreated, ECC can lead to pain and infection, as well as

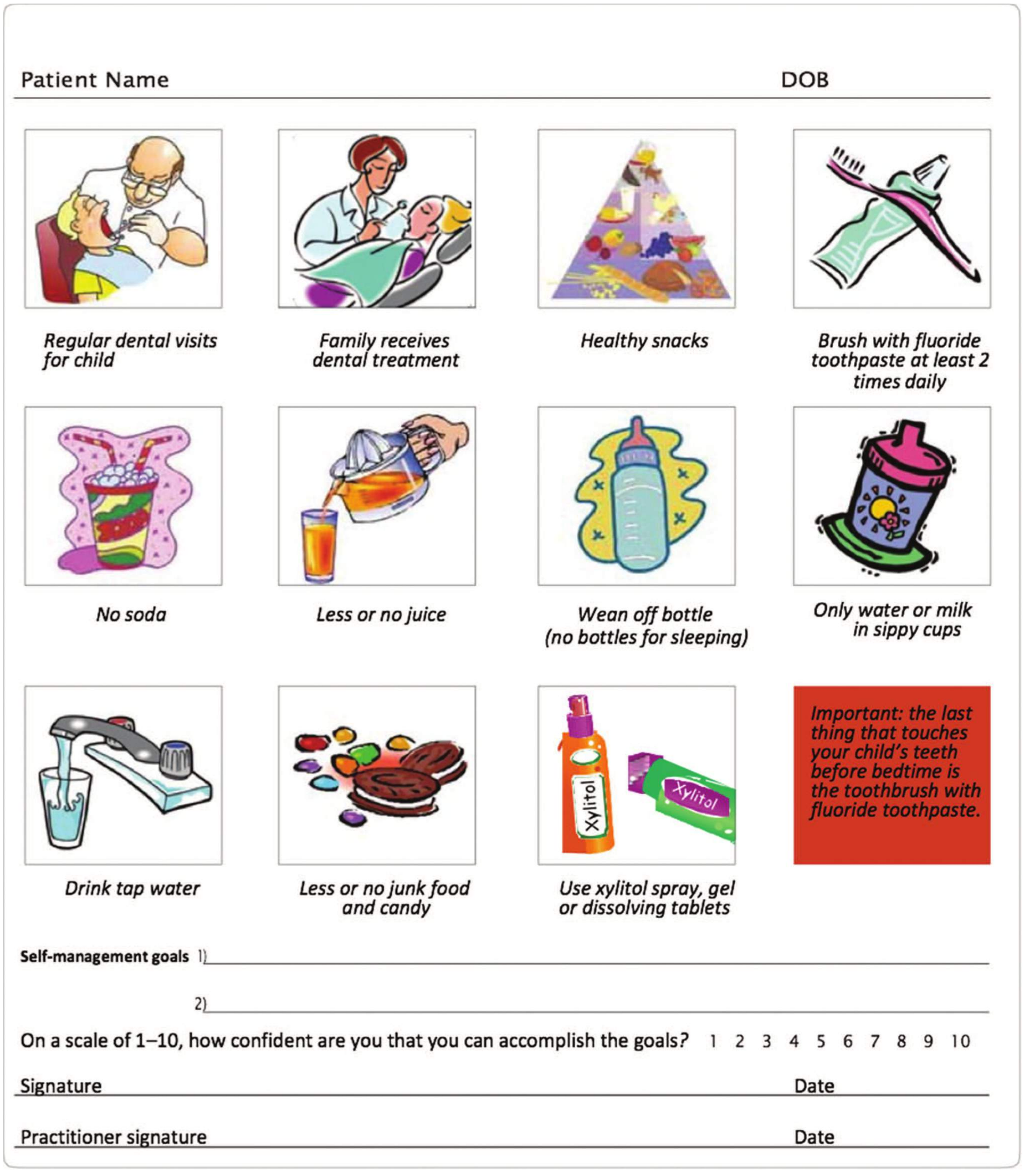


Figure 41-4. Self-management goals.

difficulty speaking, eating, and thus learning. Oral disease can have an impact on appetite and lead to depression and distractibility in school.[29] These difficulties can have effects on cognitive development, school readiness, and self-esteem, increasing the child's risk of school failure, while reducing the child's quality of life. While ECC, by definition, is found only in children, its effects, including a dramatically increased risk of caries in the mixed and permanent dentition, often persist into adulthood. But despite its high prevalence, ECC is highly treatable and even preventable. The American Dental Association and the American Academy of Pediatrics both recommend that infant be seen by a dentist by age 1, or within 6 months of the eruption of the first tooth.[30,31] However, the catchphrase "Two is too late!" has yet to be fully embraced by caregivers, and even by many dentists and pediatricians.

The key to good oral health in children is to begin early with preventive care and risk assessment.[32] Consumption of limited amounts of fluoridated drinking water during infancy can help lay the foundation for healthy teeth. Once teeth have erupted, brushing with a small smear of fluoridated toothpaste twice per day and limiting the consumption of juices and sugary snacks help prevent ECC. At the child's first dental visit, the oral health-care provider should complete a caries risk assessment, such as Caries Management by Risk Assessment (CAMBRA),[33] to determine risk level and help the child's caregiver set self-management goals (Figures 41-5 and 41-6). For those infants determined to be at moderate or high risk of ECC, the provider may elect to apply fluoride varnish.

There are, however, several obstacles to obtaining early, preventive dental care for infants and young children. Many dentists in the United States do not accept patients younger than age 3, and a large proportion of pediatricians do not incorporate oral health evaluations or counseling into their practices. Even when pediatric dentists are available, many do not accept government-based dental insurance such as Medicaid, a fact that prevents many at-risk



Figure 41-5. Early caries (cavity) lesion of a primary first molar (arrow).



Figure 41-6. Periodontal "gum" disease.

children from obtaining care. Perhaps one of the biggest issues is the "drill and fill" nature of many dental practices, where surgical interventions are the norm, and preventive care is deemed financially impractical, as insurance reimbursement rates are much higher for repairs after oral disease has already taken hold, than for early and regular case management aimed at preventing ECC.

ADOLESCENT/YOUNG ADULT ORAL HEALTH

Adolescence is a time of great developmental change. That includes a worsening of nutritional and self-care habits, and an increase in high-risk behaviors, including increased risk of trauma and exposure to negative substances such as alcohol, tobacco, or other illicit drugs. Moreover, adolescents are less likely to seek routine preventive care. Box 41-2 presents the "distinctive needs" of adolescents.[34]

Nearly half of children aged 6–19 years in the United States have caries in their permanent dentition.[35] Furthermore, dental caries is highly concentrated among children from low-income and vulnerable populations, with 80% of the decay found in 25% of children aged 5–17 years.[36] The adolescent (10–18 years) and young adult (19–24 years old) age groups are noted for changing dietary behaviors, particularly an increased consumption of dietary sugars

Box 41-2. Risk Factors for Poor Adolescent Oral Health

- High caries risk and rate
- High risk for trauma
- High risk for periodontal disease
- Developing poor nutritional habits, and eating disorders
- Need for orthodontic or restorative dental treatment
- Increasing esthetic awareness and demands
- Potential use of alcohol, tobacco, and other illicit drugs
- Pregnancy
- Unique social and psychological needs

in their nutritional patterns, and possibly a decline in the consistency and effectiveness of oral hygiene routines.[34] Both of these behavior patterns can lead to an increase in risk for dental caries.[37] Lower utilization of preventive and treatment-focused dental services for this age range is reported, particularly for those without insurance or with low family income.[38]

The LCT recognizes this stage of development as a "critical or sensitive" period, noting greater impact on health trajectory along with early childhood and pregnancy.[16] As adolescents experience additional freedoms and independence in this phase, perhaps increased access to disposable income and greater control over life choices including diet, hygiene habits, and sexual/substance use patterns, to name a few, can lead to greater caries susceptibility. For instance, increased consumption (both in frequency and quantity) of acidic and sugar-sweetened beverages, including sports and energy drinks, has been widely reported.[39-41] Further compounding caries risk, oral health education on lifestyle choices, particularly sugar consumption and dental caries susceptibility, may be particularly ineffective in this age range.[42] School absences or restricted activity days related to oral health problems account for over 1.5 million absences per year, or about 51 million school hours.[43] Children from low-income families had over 12 times as many school absences compared with their higher income counterparts.[36] School-based oral health programs and dental comprehensive care clinics in schools allow children to avoid access, transportation, and other barriers to care, and also lessen the number of missed or reduced-activity school hours.

THE ELDERLY

Elderly Americans are at significant risk for dental disease. They have had the longest cumulative opportunity to develop caries or periodontitis, or lose teeth. The elderly are more likely to have chronic disease, take medications, and be physically unable to care for their dentition (e.g., a patient with arthritis). Moreover, living on a fixed retirement income and the termination of employment-associated benefits prevent many elders from seeking care. Severe periodontal disease, in which more than 6 mm of attachment around the teeth is lost, is present in 14% of the population aged 45–54 years, increasing to 23% in those aged 65–74 years.[2] One in four adults aged 65 and older in the United States are completely edentulous.[44]

Salivary gland function naturally decreases with aging and results in drying of the oral cavity or the development of disease processes. Previous radiation therapy or over 400 commonly used medications can worsen salivary gland function. Without the antimicrobial and acid neutralizing effect of saliva, the demineralization–remineralization balance tips toward caries production. The likelihood of exposed root structure (the part of the tooth that is significantly softer and more prone to caries) resulting from periodontal disease increases the propensity for dental caries in the elderly.

ASSURING DENTAL HEALTH

Perhaps the most difficult challenge to assuring dental health is motivating patients to value and seek dental care in a preventive and nonsurgical mode. Oral health may not be a patient priority when there is no pain involved; furthermore, some cultures believe that "baby teeth do not matter," thus decreasing the incentive to take care of them. Clinicians should emphasize a proactive approach, encouraging patients to have routine checkups, maintenance, and preventive services. Routine fluoride varnish applications have been found to significantly reduce the incidence of tooth decay,[45] and should be used rather than waiting until surgical repair is necessary (Box 41-3).

ORAL HYGIENE AND REGULAR VISITS TO THE DENTIST

> Juana has had few interactions with dentistry in her lifetime and has never been taught the importance of home care and diet. Neither her friends nor her extended family value dentistry, and tooth extraction is a common means of treating tooth pain. Her two sons have never seen a dentist.

Incorporation of home care and regular visits to the dentist is vital for the maintenance of a healthy mouth. Tooth brushing removes plaque and/or biofilm from the teeth and gums, limiting the fermentable carbohydrates used

Box 41-3. Keys to a Successful Program of Prevention

- Stress the importance of oral hygiene and the importance of establishing a dental home, a regular place where oral care is received, especially among children.
- Educate women and expecting parents early in the prenatal or preconception phases on good oral health home practices.
- Educate parents, children, and health-care providers that oral health is a key to overall health.
- Provide nutrition counseling to prevent caries in children and adults.
- Use fluoride and sealants as caries-preventive measures.
- Reach out to underserved groups and incorporate dental screenings into medical examinations.

by bacteria to proliferate and produce acid. The use of an American Dental Association–approved toothpaste containing fluoride adds an antibacterial action, as well as a remineralization source for cavitated teeth. Flossing removes plaque between the teeth, where most adult cavities occur. As a general guideline, dentists recommend that their patients floss once a day and brush at least twice daily, after breakfast and dinner.

Regular visits to a dentist allow providers to check for disease present in or around the oral structures. Many dentists begin their evaluation by performing an extraoral screening: an examination of the extraoral tissues of the head and neck, and palpation of these tissues to confirm health. Radiographs, if deemed necessary, are taken of the patient's teeth and/or jaws. An intraoral examination follows to assess the patient's home care and the presence or absence of disease. Treatment appointments are then scheduled.

Without adequate brushing and flossing, the incidence of dental caries and gingivitis/periodontitis increases dramatically. The presence of plaque or biofilm produced by bacterial fermentation of carbohydrates is a critical component of the dental caries and periodontal disease process. Those patients with little or no home care due to lack of dental knowledge, a physical or mental handicap, or habitual poor oral hygiene are the most at risk for oral disease.

At-risk children and adults, especially those with conditions that may affect oral health, should have regular oral examinations as well. Women should be educated by their medical and dental providers on the importance of dental care during pregnancy, the importance of a healthful diet and vitamin supplements, and on safety concerns of pregnancy, such as exposure to substances or diseases that may have a detrimental effect on fetal dentition formation. Newly diagnosed diabetic patients should be referred to a dentist for examination and counseling. At this visit, the dentist will review the increased risk of periodontal disease with the patient and emphasize the importance of home care and an increased frequency of office visits (Figure 41-5). Similarly, women at the first sign of pregnancy and children with the first sign of a tooth should be referred. The elderly and the physically and mentally disabled should visit the dentist on at least an annual basis because they are at greater risk for caries.

Tobacco users should be encouraged to quit and screened for oral disease. In particular, tobacco use is a risk factor for oral cavity and pharyngeal cancers, periodontal diseases, candidiasis, and dental caries, among other diseases. Tobacco-related oral lesions are prevalent users of smokeless tobacco, as young as adolescents. Patients undergoing radiation therapy or chemotherapy, especially for head and neck cancers, should be referred immediately for an oral evaluation. These therapies may damage salivary glands and increase the likelihood of ulcers, fungal infections, and caries in the mouth.

It should be the goal of health-care providers to encourage patients to establish a dental home (an office or clinic in which the patient maintains a relationship with the dental providers through repeated visits) by the age of 1. Regular care instills patient–provider trust and increases the chance of returning for regular care.[46] Incorporation of tooth brushing and a sealants program into day care programs and public schools can benefit children of all communities.

EARLY DETECTION AND INTERVENTION IN CHILDREN

Health-care providers should examine children's teeth for defects and cavities at every well-child visit (see "Core Competencies"). All children should be referred to a dentist by 12 months of age, for preventive services, but this is particularly important for any child with significant risk factors for caries, such as poor oral hygiene, inadequate home dental care, premature birth, caregiver with many cavities, high sugar intake, enamel defects, special health-care needs, low socioeconomic status, and/or spot lesions. Oral health-care providers should conduct a clinical exam that includes caries risk assessment, toothbrush prophylaxis, fluoride varnish treatment, and anticipatory guidance.

Caries risk can be easily assessed by dental or health-care professionals using the CAMBRA (Figure 41-5),[33] a tool designed to determine individual caries risk and create an appropriate disease management plan (Figure 41-6), which includes prevention strategies. Health-care professionals may also opt to use the American Academy of Pediatrics Oral Health Risk Assessment Tool.[47] Given the essential role fluoride plays in the prevention of dental caries, anticipatory guidance should include instruction on tooth brushing with fluoridated toothpaste, the establishment of a dental home, and counseling on self-management goals for the parent/caregiver and the child, based on the caries risk assessment.[48] Self-management goals should be patient centered and tailored to individual risk factors for oral disease. It is vital to engage parents/caregivers in this process, and to address family beliefs and practices surrounding diet, bottle feeding, brushing with fluoridated toothpaste, and the importance of healthy baby teeth.

Traditionally, pediatric dentistry has relied on restorative procedures over preventive measures in the treatment of ECC. More modern approaches, such as the disease management paradigm,[49] emphasize the role of the patient in the prevention and management of his or her health/condition. In the case of young children, this also includes the participation of the patient's parents or

caregivers. Dental providers teach patients/parents about factors and behaviors that increase risk for or provide protection from ECC, and help them set self-management goals. The success of the disease management paradigm is dependent on collaboration between the patient and health-care provider, and thus requires trust and effective communication, both of which are fostered by culturally and linguistically appropriate interaction. Minimally invasive treatment may also include appropriate use of topical and systemic fluorides.

THE USE OF FLUORIDES AND SEALANTS

Fluoride is a powerful tool to fight cavities. The presence of fluoride during tooth development (from birth to approximately age 16) creates teeth with stronger enamel and a higher caries resistance. Fluoride comes in the form of water, tablets, gels, varnishes, sealants, and tooth paste. Water fluoridation in particular is very effective at reducing caries incidence.[50] A 0.4- to 1.0-ppm fluoride concentration in water sources is recommended as therapeutic without causing fluorosis and mottled teeth.[2] A public health plan to fluoridate community water supply began in 1945 in Michigan and New York. Nevertheless, more than 108 million Americans today have no access to community fluoridated water.

Health-care providers should evaluate their communities' water sources for fluoride content and supplement dentate children with oral tablets, accordingly. Application of fluoride gels and varnishes at schools and medical and dental facilities can greatly reduce caries rates among children.

Fluoride varnish efficacy in this age group provides additional rationale for an early dental visit, especially for children in high caries risk groups, because application at this first visit and counseling based on anticipatory guidance will help reduce future dental disease in young children.[51]

The application of sealants to children's permanent first molars also has been highly successful as a means of preventing occlusive (biting) surface decay.[52] Teeth deemed susceptible to decay on the occlusive surface, usually first molars in children and adolescents, are cleaned with a special paste, etched with phosphoric acid, and painted with a resin that flows into the fissures of the tooth. The covered fissures now prevent food collection in this area and make cleaning these teeth easier.

The efficacy and safety of using fluoride toothpaste in young children has been assessed through a systematic review by the American Dental Association (ADA). Results demonstrated that for children younger than 6 years, fluoride toothpaste use is effective in reducing caries, but can also lead to mild fluorosis when pea-sized amounts, or more, are ingested.[53] It is difficult to predict a child's likelihood of developing dental caries in their primary teeth, since the best predictor of a person's developing dental caries in the future is the current presence of dental caries, and most 1-year-old children do not have dental caries. Therefore, considering the best available evidence and the continued high caries rate in children, the ADA recommends the following: (a) caregivers of children younger than 3 years should brush the child's teeth with fluoride toothpaste, as soon as teeth erupt, using an amount no more than a smear (or grain of rice) twice per day; (b) caregivers of children between 3 and 6 years of age should brush the child's teeth thoroughly with no more than a pea-sized amount of fluoride toothpaste twice per day; and (c) dentists provide counseling to caregivers that involves the use of oral description, visual aids, and actual demonstration in order to ensure that the appropriate amount of toothpaste is used.[54]

NUTRITIONAL COUNSELING

> As the dentist discusses the factors leading to caries, Juana begins to understand her family's risk because of their diet.

Nutritional counseling is an important aspect of preventive dental care. Both diet and frequency of consumption of foods affect one's likelihood of developing cavities. As fermentable carbohydrates are ingested, the pH of the mouth drops because of acid production. Saliva then acts as a buffer and neutralizes the acid. The decline of mouth pH and subsequent neutralization is a cariogenic episode. Foods high in sugar (e.g., sodas, cookies) produce a virulent cariogenic episode, and should be eaten sparingly. Even "healthy" foods like dried fruit can be problematic for teeth, since they are concentrated carbohydrates, which stick to teeth longer than soda, leading to a prolonged cariogenic episode. However, the frequency and timing of intake is as important as the amount of sugar intake. Multiple cariogenic episodes spaced closely together are more likely to cause tooth decay than those occurring farther apart. When counseling patients regarding diet, limiting the frequency of snacking should be emphasized; "grazing" is particularly high risk. Minimizing the length of exposure to sugars also should be given special importance, especially with children. Slowly drinking sodas and eating sticky candies are considered to be long exposures. Particularly harmful are those situations where parents put their infants to bed with juices or milk. The sugars present in milk and juices sit on their teeth overnight and provide ample substrate for cariogenic bacteria. Baby bottle tooth decay can quickly decimate a child's dentition and require extensive dental treatment. Nutritional counseling is a powerful facet of preventive dentistry that any health-care worker can and should provide.

THE IMPORTANCE OF OUTREACH TO UNDERSERVED AREAS

A shortage of dental care workers in rural areas is evident. Many have no physical access to dental care, nor opportunity for dental education. More than 12% of Americans live in medically underserved areas, where there are high levels of poverty, increased infant mortality rates, or a high concentration of elderly residents. They may also be in areas where there is a shortage of primary care physicians, known as health professional shortage areas, and in the oral health arena, dental health professional shortage areas (dHPSA). People from these areas may or may not have other characteristics that would qualify them as underserved. There may be a high number of dentists in a dHPSA, but very few of them may accept Medicaid or government-based dental coverage.[55] In fact, fewer than 25% of US dentists see 100 or more Medicaid patients per year. Low Medicaid reimbursement rates are often a factor in low provider acceptance. Medicaid is the major payor of dental services for the underserved in the United States, and each state has different coverage, varying with age. Currently, Medicare does not cover any dental services.

Thus, new means are needed for outreach to the underserved population. One tactic is to incorporate oral health education and screening into medical care. Schools can also provide oral health education and prevention. Preschools, for instance, are a great forum to educate children and teachers, as well as parents, on the importance of diet and oral hygiene. Preschool and grade school visits also allow for dental screenings and the distribution of toothbrushes and toothpaste to children. The surgeon general included these in his "Call to Action" (Box 41-4).[56]

Box 41-4. 2003 US Surgeon General's National Call to Action to Promote Oral Health

- Action 1: Change perceptions of oral health (establishing a dental home, preventive care rather than reactive care, link between oral health and overall health)
- Action 2: Overcome barriers by replicating effective programs and proven efforts (water fluoridation, sealant programs, no sleeping with the bottle)
- Action 3: Build the science base and accelerate science transfer
- Action 4: Increase oral health workforce diversity, capacity, and flexibility
- Action 5: Increase collaborations (educate not only children and parents but also pediatricians, nurses, health-care providers, and day care providers)

INTERPROFESSIONAL EDUCATION AND PRACTICE

The importance of early detection of oral disease cannot be overstated. To this end, visual examination of the oral structures by all health-care providers can help patients tremendously. The presence of white spot lesions, broken teeth, oral pain, swelling, and bad breath can all indicate the presence of dental disease and mandate a referral to a dentist. Medical providers should not be afraid to educate at-risk patients on the importance of oral care and, when possible, provide a list of dental resources for the patient.

As outlined in the 2014 report by the U.S. Department of Health and Human Services report,[57] coordinated efforts by Health Services and Resource Administration (HRSA) will be focused on the following four recommendations:

1. Integrate core oral health clinical competencies into primary care settings.
2. Develop infrastructure that is interoperable, accessible across clinical settings, and that enhances the adoption of oral health clinical competencies in primary care.
3. Modify payment policies to address the implementation costs of oral health, and incentive payments to providers and health-care systems for adopting oral health clinical competencies into primary care.
4. Execute, implement, and evaluate programs adopting oral health clinical competencies into primary care.

This publication provides insight into health-care delivery and payment systems reform, as envisioned by HRSA, and, for the first time, suggests oral health clinical competencies as compulsory for primary care providers.

INTEGRATED APPROACH TO ORAL HEALTH

The Institute of Medicine (IOM) put forth a number of recommendations and strategies in their 2011 report addressing access to oral health care for vulnerable and underserved populations.[58] In this report, the IOM proposes the development of truly integrated health-care systems known as "health homes," and not just standalone "dental homes." Forward-thinking medical and dental schools have begun to emphasize interprofessional education (IPE) and interprofessional practice (IPP). This innovative approach touts the value of cross-training nondental providers (physician, nurses, etc.) in dental risk assessment, anticipatory guidance, and, in some cases, the application of fluoride varnish. Merging efforts of the entire health professions workforce could lead to improved oral health access, outcomes, and efficiency.

The existing number of dentists and hygienists in the United States is insufficient to address the needs of the nation, and the workforce distribution across the country is concentrated in and around major cities, leaving semirural

and rural Americans with inequitable access to oral health care.[59] In fact, it is estimated that nearly 9500 new dental providers are needed to meet today's needs.[60] At present, the number of dentists retiring each year exceeds the number of new dental school graduates to replace them, further compounding the future oral health workforce shortage.[60] Following in the footsteps of other countries that have faced dental workforce shortages, the United States is embarking on a number of strategies to increase those providing dental care. Educating "midlevel" dentistry providers akin to nurse practitioners is one such program that has been used successfully in over 54 countries including New Zealand and Canada as well as in Alaska and Minnesota in the United States. Dental therapists or advanced practice hygienists learn to provide basic care including filling simple cavities and simple tooth extraction.

TRAINING IN BASIC AND ROUTINE ORAL CARE

Training medical providers to do basic and routine oral care is another way of improving oral health. The American Academy of Pediatrics has set forth a list of potential roles for medical providers in achieving an integrated approach to oral health, which includes counseling, oral health disease screening, the use of fluoride varnish, screening for use of fluoride supplementation, and referring patients for comprehensive dental care.[61] The American Academy of Family Physicians and the National Association of Pediatric Nurse Practitioners have similar statements.[62,63] A number of state Medicaid programs have begun to reimburse primary care medical providers for application of fluoride varnish.[64] The American College of Obstetrics and Gynecology recommends their providers screen pregnant women at their very first prenatal visit to determine if they have seen a dentist recently, and if not to refer them to one as soon as possible.[25]

Success from planned and consistent integration with nursing students and faculty has addressed initiatives such as smoking cessation, pediatric oral health, service learning, and has produced some of the first recognized health professions faculty specifically trained in IPE.[65] Many other dental schools are engaged in multidisciplinary case conferences and case study programs with students and faculty from multiple health professions schools.[66,67] The importance of IPP and IPE has been reviewed and discussed in multiple IOM publications, supported by recent federal legislation such as the Affordable Care Act of 2010, and will continue to change and evolve to impact greater reach for underserved populations.

USE OF NONTRADITIONAL PROVIDERS

Another innovative strategy is to deliver oral health services via nontraditional providers. The IOM proposes expansion of the oral health workforce creating new categories of health professionals or case management professionals with expertise in supporting oral health. Lay health-care workers, such as promotoras, farm health workers, community dental health coordinators,[68] outreach workers, family advocates in Head Start programs, and advocates in Women Infants and Children (WIC) Supplemental Nutrition programs are being trained in dental health screening in many states and municipalities around the country. Workers conduct caries risk assessment and provide oral health–related anticipatory guidance and preventive health education, while identifying at-risk children and parents as early as possible, and since most of these workers belong to the communities in which they serve, they are particularly equipped to provide culturally competent care.

Telehealth projects, such as the Virtual Dental Home Project, use technology to enable dentists to view patients' dental records and documentation remotely, while dental hygienists and assistants provide hands-on care in underserved communities.[69] The goal of this specific intervention, if proven to be cost-effective, is to expand such programs to schools, nursing homes, and Head Start centers. Similarly, mobile dental programs can be used to serve the homeless, the elderly, migrant workers, and children under the care of Department of Children and Family Services (DCFS), as well as individuals in inner city or rural communities, while the integration of oral health-care programs into school-based health centers provides a way to reach at-risk school-aged children (Box 41-5).[70]

Box 41-5. Training Curricula

1. Help Me Smile curriculum[71]
2. Healthy Smiles: A Lay Health Worker Dental Outreach Program[72]
3. Community Health Workers Evidence-Based Models Toolbox[73]
4. Breaking Down Barriers to Oral Health for All Americans: The Community Dental Health Coordinator[68]
5. Smiles for Life: A National Oral Health Curriculum[74]

CONCLUSION

Health-care providers act as a valuable bridge between scientific research and the public need. Oral disease extends beyond the mouth, affecting patients of all ages and backgrounds, but disproportionately affecting underserved populations. Thus, a coalition of providers and approaches is needed to decrease the rates of this largely preventable disease. Any qualified health-care provider

can conduct prevention and management of oral disease in a variety of primary care settings. As many at-risk individuals are more likely to receive medical care than to seek preventive dental care, cross-trained medical or nursing personnel might be able to provide initial oral health assessments and guidance at an earlier stage. We should promote collaborative efforts with individuals, families, communities, policy-makers, and governments, to offer easily accessible and consistent oral health messages and services targeting vulnerable and at-risk populations, particularly infants and children, as the early establishment of good habits and preventive care can lead to a lifetime of good oral health.

The integration of oral health into primary care, using an interprofessional and multidisciplinary approach, is the future, and is mandatory for successfully meeting the oral health needs of vulnerable populations. Medical and dental providers, in collaboration with government, health services and media, should do their utmost to educate patients, parents, and caregivers on the tenets of oral health in a culturally and linguistically appropriate manner, as oral health literacy is, ultimately, a pathway to health equity.

- Instruct patients that caries are a transmissible disease.
- Incorporate oral screenings into overall physical examinations.
- Emphasize that diet and nutrition are critical to caries prevention.
- Encourage patients to minimize frequency of sugar intake.
- Encourage patients to establish and maintain good oral hygiene home-care routines.
- Encourage patients to establish a dental home especially:
  - before birth
  - for infants starting at age 1
  - are pregnant or expecting a child
  - the birth mother has diabetes
- Assess caries risk in children by looking for white spot lesions or brown spots.
- Daily use of fluoridated toothpaste for all ages, especially at night before going to bed.
- Discuss fluoridation and its importance in caries prevention with your patients.
- Prescribe fluoride tablets for children in communities whose water is unfluoridated.
- Consider fluoride varnishes for all children.
- Explain the importance of preventive dental care.
- Collaborate and integrate dental health programs and education into overall health systems and medical education/trainings.

Extraoral Examination:

- Examine the face and neck for symmetry, skin lesions, swelling, and overall appearance.
- Cancer screening: Palpate the lymph nodes along the sternocleidomastoid muscles and under the chin for edema or indurated masses.

Temporomandibular Examination:

- Place your pointer and middle fingers just in front of the patient's ears and have them open. Popping and clicking are a variation of normal.
- Ask the patient:
  - Have you ever had any pain in this region?
  - Have you ever had your jaw lock open or shut?
  - Do you wake up with your jaw muscles tight?
  - Do you get headaches?
  - Does your partner ever tell you that you grind your teeth?
  - Is there any deviation of the mandible upon opening?
  - Is there any limitation of opening?

A "yes" answer to any of these questions indicates referral to a dentist.

Intraoral Examination:

- Examine the soft tissues of the mouth, tongue, and throat for cancer.
  - Look inside along the cheeks for anything unusual: white, red, or mixed lesions, swelling.
  - Examine under the tongue: Palpate the floor of the mouth digitally with one hand, using the other extraorally under the chin. Feel for indurated masses.
  - Examine the lateral borders of the tongue, the roof of the mouth (palate), and back of the throat for abnormalities.
- Examine the condition of the dentition.
  - Children: Look for black spots on the biting surfaces of the teeth (Figure 41-2). These may be cavities. Ask the parent if the child is eating well or if they have any pain in his or her mouth.
  - Adults: Look for cavitations in the teeth (black staining of grooves in the teeth is not abnormal in adults.)
- Does the patient have unusually bad breath?
- Feel the teeth: Are they loose?
- Look at the gums. They should look pink and flat.
- Red, swollen, and inflamed gums indicate gingivitis or periodontal disease (Figure 41-3).

If in doubt, call your local dentist!

DISCUSSION QUESTIONS

1. Why is the treatment of dental disease important, considering the goal of treating the whole patient?
2. In what ways can rural health-care providers impact oral health in their communities?

3. If Juana walked into your office, what recommendations would you give her regarding her oral care? What concerns would you have with her children, understanding Juana's own medical and social history?
4. What are topics to discuss with pregnant women regarding their oral health status?

RESOURCES

The American Dental Association. http://www.ada.org.

American Dental Hygienists' Association. http://www.adha.org/oralhealth/.

The Center to Address Disparities in Children's Oral Health. http://www.ucsf.edu/cando/.

First Smiles is a statewide initiative to address the "silent epidemic" of Early Childhood Caries affecting children ages 0–5. http://www.first5oralhealth.org/.

National Institute of Dental and Craniofacial Research. http://www.nidcr.nih.gov/.

The oral-systemic health connection. National Institute of Dental and Craniofacial Research, National Institutes of Health. Accessed June 1, 2006. http://www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/OralSystemicHealthConnection/OralSystemic.htm.

http://www.astdd.org/school-and-adolescent-oral-health-committee/

http://www2.aap.org/oralhealth/

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Chapter 42

Disability and Patients with Disabilities

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Objectives

- Define the concept of disability.
- Review the epidemiology of disabilities among community-dwelling persons.
- Describe key social, legal, and health policy issues relating to disability.
- Describe issues raised by disabilities related to vision, hearing, and lower extremity mobility difficulties and strategies to improve these.
- Describe accessibility considerations for health-care settings.

INTRODUCTION

According to the 2011 World Report on Disability, approximately 1 billion people worldwide live with disability.[1] The U.S. Census Bureau puts the number of Americans with disabilities at roughly 57 million or about 19% of the population.[2] Both in the United States and around the globe, persons with disabilities are much more likely than others to experience significant disadvantages in education, employment, income, housing, and transportation, as well as other eco-social determinants of health.[1,3] In addition, people with disabilities often experience disparities in their health care, for example, receiving fewer screening and preventive services than do persons without disabilities. People with disabilities are more likely to experience inactivity, putting them at higher risk of chronic diseases. On average, individuals with disabilities are much more likely to report fair or poor health than are nondisabled persons.

Disabilities are diverse in their causes, nature, timing, pace, and personal and social implications. Some are congenital, others acquired. Some arrive suddenly with injury or accident; others progress slowly over time. Some gradually limit but do not threaten life; others hasten death. Some are visible to outsiders; others remain hidden. Some engender stigmatization and blame; others prompt pity and paternalism. Some are seen primarily as "diseases" (e.g., end-stage cancer, emphysema, schizophrenia), even when profoundly disabling. Anyone can become disabled, and in the fullness of time, most people do.

Given this diversity, speaking of "persons with disabilities" as a single subpopulation is almost meaningless. Even within categories of impairments—such as lower extremity mobility difficulties—the causes, manifestations, and clinical implications are wide ranging. This chapter does not discuss specific medical conditions that cause disabilities. Instead, it offers an overview of the key social and health policy issues and selected major practice concerns raised by disability, focusing on persons with disabilities related to seeing, hearing, and walking. For convenience, this chapter uses the term "disability" when referring to sensory or physical impairments. Nonetheless, it makes no presumption that individuals with these conditions are, in fact, disabled, however they choose to define the word. People with other potentially disabling conditions, such as serious and persistent mental illness or developmental

disability, might require somewhat different assessments or accommodations than those described later.

DEFINING DISABILITY

> Judy, in her late 20s, was born to deaf parents who themselves had deaf parents. Judy is third-generation deaf. Judy's family speaks American Sign Language (ASL), which also was the language used at her Deaf school. She later learned English and now works in the hearing world, relying on lip reading and ASL interpreters. Judy does not view herself as disabled, but instead as belonging to the Deaf linguistic minority culture.

Identifying individuals as disabled is complex, with multilayered personal, administrative, legal, and societal ramifications. Over the last century, various definitions of disability have appeared for diverse purposes, with little consensus across definitions. A "medical model" treats disability "as a problem of the person, directly caused by disease, trauma, or other health condition, which requires medical care. Management of the disability is aimed at cure or the individual's adjustment and behavior change."[1,2] In the past 50 years, a "social model" has viewed disability "mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment."[2] Judy, for example, sees communication problems she confronts in her workplace not as her personal deficit, but as failures of the majority hearing world to accommodate communication with a linguistic minority.

In 2001, the World Health Organization approved the International Classification of Functioning, Disability and Health (ICF), which attempts to integrate medical and social models of disability.[2,3] The ICF identifies three interrelated concepts: "Impairments are problems in body function or structure such as a significant deviation or loss. Activity is the execution of a task or action by an individual. [and] Participation is involvement in a life situation." The ICF defines disability as an "umbrella term for impairments, activity limitations or participation restrictions," conceiving "a person's functioning and disability … as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors," including environmental and personal attributes.[2] As discussed in the following, the Americans with Disabilities Act (ADA, P.L. 101-336) adopted an even more expansive definition of disability.

> Whenever she goes to the doctor, Judy says, the first question is always about why she is deaf: "I was just born that way." She wants the first question to address her chief complaint.

Today's broad definition of disability carries important lessons for clinicians, primarily because of potential effects on patient–clinician communication and incorporating the disability appropriately into treatment plans. Clinicians should approach clinical encounters with persons with disabilities just as they do with other patients, starting with the chief complaint and then, as necessary, learning more about any impairments when asking history questions. It is useful for the clinician to learn the patient's view of the impairment. In some instances, impairments may be irrelevant to the reason patients seek care. For example, Judy's identification as a linguistic minority rather than as someone with a disability should be known and respected, regardless of how social programs or legal mandates would categorize her.

In addition, the social definition highlights the relationships between individuals and their daily environments. Interventions that affect the interplay between them (e.g., various assistive technologies) or even the environment itself (e.g., ramps at home entrances) may prove extremely efficacious in restoring persons to safe and independent functioning; thus, the health care provider's role in "treating" disability includes adjustments not only to the impairment, but in recommended adjustments to the environment and the interplay between them.

EPIDEMIOLOGY

Varying definitions impede efforts to determine the population prevalence of disability. Patterns of disability (e.g., by age, sex) vary depending on perspective. Nearly 20% of community-dwelling, civilian, US residents aged 5 years and older report at least some disabling condition, with rates rising sharply (to 50%) among persons aged 65 and older.[2] As noted earlier, disability frequently tracks with personal attributes that characterize vulnerable populations, including minority race, low educational attainment, high level of unemployment, and poverty.

Conditions relating to aging are the most common causes of sensory and physical disabilities. Cataracts and glaucoma, along with presbyopia, are the main causes of vision loss[4]; presbycusis is the most common reason for hearing loss[5]; and arthritis is the single most disabling condition among adult Americans.[5] Overall, because of very high rates of hearing problems among white men, white persons are more likely than African-American, Hispanic, and other race individuals to report any sensory or mobility disability. However, African Americans report higher rates of mobility disabilities than do whites; relative rates for Hispanics vary depending on the nature of the physical impairment.

OVERVIEW OF SOCIAL, LEGAL, AND HEALTH POLICY ISSUES

Jimmy, a man in his mid-40s, has painful arthritis in his hips and knees, which sometimes causes him to fall. He worked moving boxes in a warehouse, but the physical demands of his job seemed too much for him and his employer fired him. Out of a job, Jimmy is unable to sustain his level of living and seeks public assistance. He asks his physician to write a disability letter in support of his Social Security Disability Insurance (SSDI) application.

SOCIAL SECURITY PROGRAMS

In the late 1950s, Social Security began two programs authorizing cash benefits for persons, such as Jimmy, who cannot work because of disability: SSDI (under Title II of the Social Security Act) and Supplemental Security Income (SSI, under Title XVI). SSDI gives benefits to persons who are "insured" by virtue of having worked and contributed to the Social Security trust fund through withholdings on their earnings (SSDI also covers certain disabled dependents of insured persons). The 1972 Social Security Act amendments granted eligibility for Medicare to individuals who have received SSDI cash benefits for 2 years. Title XVI provides SSI payments to persons, including children, who are disabled, blind, or elderly and have passed a means test documenting limited income and resources. Persons qualifying for SSI immediately receive Medicaid coverage. Poor persons receiving SSDI also can obtain SSI benefits after passing the means test; some states supplement the federal income benefit with additional cash payments.

SSDI and SSI use identical definitions to determine whether working-age adults are "disabled": Under a yes/no standard, persons either can or cannot engage in "substantial gainful activity" because of medically proven sensory, physical, or mental impairments.[6] As codified by 1968 regulations, the disability evaluation starts with the "Listings of Impairments" (the so-called List), which itemizes impairments, grouped by body system, that should be sufficiently severe to preclude substantial gainful employment among adults.[7] The List stipulates specific tests (e.g., radiographs) and physical examination findings (e.g., joint range of motion) required to validate each condition. Musculoskeletal conditions are the leading cause of disability eligibility.[7]

PHYSICIAN ROLE IN ELIGIBILITY ASSESSMENT

Typically, officials determining eligibility seek information from applicants' own physicians, presuming that they have the greatest clinical knowledge of their patients' conditions. Thus, when Jimmy sought benefits from Social Security, he was referred to his physician for an evaluation and completion of the appropriate paperwork. This sometimes causes tensions between patients and physicians, especially when physicians think that patients can still work and the patient disagrees. After all, physicians must document all forms honestly, based on their professional judgments. In such instances, physicians should thoroughly explore the reasons why persons wish to stop working. For example, in Jimmy's case, his physician might believe that he is not significantly impaired and could work at another job requiring less physical labor.

How disagreements between patients and physicians are handled often depends on the nature of the interpersonal and professional relationships. When there is disagreement, one strategy is to show the patient the final evaluation, asking if he or she would like the physician to submit it. Often, if the patient is unhappy, he or she may simply seek the advice of another physician. Finally, it is important to note that in the final analysis, it is not the clinician who grants disability, but it is the agency or courts (see "Core Competency").

AMERICANS WITH DISABILITIES ACT

Given his financial straits, Jimmy sometimes wonders whether he should have tried to continue working, suing his company under the Americans with Disabilities Act for a job that would have been less physically demanding.

According to its opening statement, the aim of the Americans with Disabilities Act is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." Title I charges the Equal Employment Opportunity Commission, established initially with the Civil Rights Act of 1964, with ensuring that employers do not discriminate because of disability against otherwise qualified individuals "in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment" (Sec. 102(a)). Discrimination includes "not making reasonable accommodations to the known physical or mental limitations" (Sec. 102(b)(5)(A)). Title II prohibits discrimination or denial of services provided by public entities, while Title III prohibits discrimination involving public accommodations and services operated by private entities, including the "professional office of a health care provider, hospital, or other service establishment" (Sec. 301(7)(F)).

The ADA defines disability as: "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having

such an impairment" (Sec. 3(2)). In operationalizing this definition, the ADA differs fundamentally from other civil rights laws. For instance, to sue for racial or gender discrimination, plaintiffs do not need to prove that they belong to a particular race or gender group. However, to litigate under the ADA, individuals must prove, sometimes to a skeptical judiciary, that they are disabled before they can broach questions about discrimination.

Through various cases (Sutton et al. v. United Air Lines, Inc. and Murphy v. United Parcel Service, Inc., 1999; Toyota Motor Manufacturing Inc. v. Williams, 2002), the US Supreme Court further constrained the ADA's reach, largely by delimiting the "major life activities" clause. Rejecting Supreme Court holdings in such cases, the Congress passed the Americans with Disabilities Amendments Act (ADAAA), which was signed into law in 2008. The ADAAA aims to broaden coverage by including lists of conditions that qualify as disabilities and eliminating other strictures that limited disability claims. Under ADAAA provisions, with his physician's assertions about his debilitating lower extremity arthritis and difficulty working, Jimmy might pass muster as "disabled" even though he still functions around home, doing light chores and preparing meals.

Having a disability can have a profound effect on the health care one receives. Providers often:

- Fail to seek the patient's perspective on his or her impairments.
- Assume that the disability is the reason the patient is seeking care.
- Are unfamiliar with the assistive devices that may help their patient.
- Are not adequately trained to assess the disability.
- Do not have or make appropriate use of adaptive equipment in their work setting.
- Struggle with applications for disability benefits.

LOWER EXTREMITY MOBILITY DIFFICULTIES

> Tom's wife is both irritated and worried. Tom, a shop clerk in his mid-40s, refuses to acknowledge the foot drop that is making him fall ever more frequently. He will not even tell the clinic doctor about it.

Walking not only physically moves persons at will from point A to point B, but it also carries tremendous cultural significance. The US ethos assumes citizens are free to move at will, act independently, be self-reliant, and take control, not be a burden to others. Bipedal, upright movement permeates aphorisms, connoting independence, autonomy, perseverance, strength, achievement: "standing on your own two feet," "walking tall," "standing up for yourself," "taking things in stride," and "climbing the ladder of success." If their walking progressively fails, people can become embarrassed, ashamed, terrified of losing control, and afraid of being called lazy. Especially when older, people can feel that worsening walking is inevitable, something to be borne without complaint and hidden from view, something physicians can do little to help.[8] Some, such as Tom, believe they can beat the problem by sheer willpower. In addition, Tom fears, not without reason, that he will lose his job if his boss notices his increasing debility.

THE ACT OF WALKING

Walking involves multiple interactive components, including gait, balance, strength, and endurance. Gait is the physical action of walking—a repeating cycle of movements encompassing one step with each foot. The gait cycle involves the stance phase (about 60% of the gait cycle) and the swing phase (the other 40%). The stance phase splits further into the double-leg stance (both feet contacting the ground) and the single-leg stance. One way to increase stability is to increase the time spent in double-leg stance. As people age, stride length shortens, thus resulting in larger proportions of walking time spent with two-leg support.

During the gait cycle, a person's center of mass (COM, located midway between the hips) moves rhythmically up and down and side to side, while transferring weight from one leg to the other. People naturally adjust their limb and trunk muscles, counterbalancing arm swings and walking speeds to minimize COM movements and maintain their balance (the ability to control upright posture). Abnormalities that distort smooth, wavelike COM movement, such as the hemiplegic gait of strokes or efforts to avoid weight bearing on painful hips or knees, increase the energy required to walk. Walking slowly actually demands more energy for muscles and other structures to provide additional balance. If persons with impairments walk slowly, they therefore consume more energy than do others while walking the same distance.

TAKING A WALKING HISTORY AND EVALUATING MOBILITY

Asking about physical activity should be part of a complete primary care evaluation. Patients' abilities to walk distances or perform other physical activities have long been used as explicit clinical indicators of cardiorespiratory endurance. Carefully questioning patients with, for example, heart failure or chronic obstructive pulmonary disease about how far they can walk before becoming

short of breath provides important information about the severity of those diseases. Sometimes clinicians make patients walk around the office while monitoring their oxygenation via an oximeter. However, this does not constitute a formal gait analysis.

Major primary care textbooks say little about evaluating gait, and primary care clinicians often fail to recognize fully patients' functional deficits. Some primary care clinicians observe patients as they walk into examining rooms or climb onto examining tables; however, these efforts are neither rigorous nor consistent. Only a few ask their patients to walk down the corridor and formally evaluate their gait. Evaluation tools do exist to assess walking, requiring nothing more sophisticated than a hallway, chair, and stopwatch. One that has been validated for elderly populations is the "Get Up and Go Test."[9] At a minimum, assessments provide a critical baseline evaluation (Box 42-1).

Getting patients such as Tom to describe their difficulty walking can take careful questioning, cautiously circling the issue. Clinicians could begin with a series of questions: Do you ever have trouble walking across the street before the light changes? Tell me about the last time you walked around your neighborhood. What do you hold onto when you walk around your house? How many times a day do you walk up and down stairs? Have you fallen in the past year? How much do you worry about falling? Family members, such as Tom's wife, can volunteer important insight, albeit sometimes at the cost of interpersonal harmony. Obviously, additional questions should target specific diagnostic possibilities (e.g., asking about pain, muscle weakness). As in Tom's case, if patients report falls, questions should address potential precipitants and elicit information that could assist in designing strategies to prevent falls.

Tip: Traffic signals at standard cross-walks are timed to normal adult gait speed. If your patient regularly has difficulty crossing the cross-walks prior to the "Don't Walk" signal, he or she may have a gait disorder.

Box 42-1. The "Get Up and Go" Test

Instruct patient to:

- Rise from sitting position
- Walk 10 feet
- Turn around
- Return to seated position in chair

Taking more than 30 seconds to complete this task suggests higher rates of dependence and risk of falls; less than 20 seconds suggests independence for transfers and mobility.

Source: From Podsiadlo and Richardson.[10]

REFERRALS TO REHABILITATION SPECIALISTS

> His physician plans to work up Tom's drop foot, but in the meantime he refers Tom to a physical therapist for evaluation, potential strengthening and balance exercises, and to learn how to prevent falls or at least minimize injury when falls do occur.

Primary care clinicians are not typically trained to perform detailed functional evaluations or recommend specific exercises or other clinical interventions or assess persons for assistive technologies, such as mobility aids.[10] When patients have important and active medical issues affecting their function, physical medicine and rehabilitation (PM&R) physicians (also known as physiatrists) can help. They assess functional needs and provide nonsurgical interventions, frequently working alongside physical and occupational therapists. By fully understanding complex medical factors, as well as the nature of impairments, PM&R specialists aim to construct care plans that maximize health and independent functioning. Table 42-1 shows guidelines of appropriate referral to physical or occupational therapists.

AMBULATION AIDS AND WHEELED MOBILITY AIDS

> Tom's physician recommends a cane to assist with balance and help prevent falls.

Mobility aids fall into two broad classes, depending on whether they assist or replace ambulation. These aids can restore functional independence to persons unable to walk

Table 42-1. Guidelines for Appropriate Referrals to Rehabilitation Specialists

Referrals to physical therapists are appropriate when patients:
Are adapting to new disability
Have significant balance or gait disturbance
Have significant range of motion or strength impairments
Need assessment for a mobility aid
Need training in use of ambulatory aid
Have seating or positioning problems with a wheelchair
Referrals to occupational therapists are indicated when patients:
Are adapting to new disability
Need assistance with basic or instrumental activities of daily living
Display limited judgment about safety
Need splint or orthotic fabrication
Need adaptive equipment for work
Require assessment of home environment for possible modification to improve safety and usability

safely without them. The proper choice depends on the cause of the mobility difficulty, the setting in which the person will use the aid, and the person's physical condition (e.g., endurance, upper and lower body strength, hand strength and dexterity, balance, truncal stability), cognition, judgment, vision, and hearing. Some people may benefit from having more than one type of aid for use in different circumstances. Ambulation aids include canes, crutches, knee walkers, and walkers (with and without wheels), whereas wheeled mobility aids include manual and power wheelchairs and scooters. To use ambulation aids, persons must have adequate shoulder, arm, and hand functioning.

Historically, mobility aids had distinctly institutional appearances, underscoring images of debility. Now, diverse manufacturers compete to provide mobility aids meeting all consumer demands and needs, including children's crutches in fluorescent colors, canes decorated with elaborate carvings or paintings, rolling walkers with seats and baskets, lightweight manual wheelchairs in rainbow hues, and specialized wheelchairs for sports from racing to basketball. Language is also shifting. The phrases "wheelchair bound" and "confined to a wheelchair" imply passivity and are simply wrong (i.e., no one spends every minute in a wheelchair). Today's preferred phrase—"wheelchair user"—is simple and accurate, reflecting action.

CANES

Canes can aid balance and offload weight. Although multiple styles of canes exist (standard, offset, and multilegged), little research has explored the optimal cane for different situations, and often the choice comes down to personal preference and availability. All canes offer an additional point of contact with the ground and thus widen persons' base of support. Offset canes bear weight better than standard canes, but multilegged canes may be best for that purpose. Regardless of the style, canes must be the proper height and used correctly to maximize their utility. For increasing balance, patients should place the cane in their dominant hand; the extrasensory input from the hand-cane-ground contacts helps improve balance. For offloading weight, persons hold the cane in the hand opposite the weak or painful leg (e.g., persons with right knee problems should use the left hand). When taking a step, persons should advance their cane along with their problem leg, allowing some weight to shift from that leg to their arm and the cane.

CRUTCHES

Unlike canes, crutches can bear a person's full weight, assuming the individual has sufficient upper body strength. Crutches also increase the lateral base of support and thus improve stability. The two classes of crutches are axillary and forearm models. Because they require considerable upper body strength, axillary crutches are most appropriate for temporary complete weight bearing following an injury. Forearm crutches, also called Canadian crutches, require triceps strength but allow the hands to be free when not walking. Persons with partial paralysis or lower extremity amputations can use forearm crutches to offload weight.

KNEE WALKERS

Knee walkers can be used by individuals with foot and ankle impairments. As they do not require upper extremity strength, they can be useful for individuals who have difficulty using crutches. Like wheeled walkers, they require significant attention from their users. Unlike crutches, knee walkers cannot be used on stairs.

WALKERS

Numerous models of walkers now exist: standard four-point walkers without wheels; walkers with wheels in front but not in the back; and walkers with three or four wheels, brakes on their handlebars, seats, and baskets. Depending on their style, walkers greatly increase stability and balance. Wheeled walkers minimize the energy demands of their use, but require greater attention and care from users. As with canes and crutches, walkers must be set to an appropriate height for the individual user, and optimally physical therapists would train persons in proper use of their walker.

> Tom's leg weakness worsens, preventing him from walking long distances. His wife has an old, institutional wheelchair hidden away, left behind from her mother's final illness. Would that help Tom?

WHEELCHAIRS

Most assume that when people are seated they are safe and comfortable. Nothing is further from the truth. Standard chrome wheelchairs, with plastic sling backs and seats used to ferry people around hospitals and airports, generally are uncomfortable to occupy for lengthy periods. "Seating" is now a science. Engineers and materials specialists design wheelchairs and wheelchair cushions specifically to maximize safety, comfort, and functionality, with adequate back supports, padding for vulnerable sites (e.g., ischial tuberosities) to minimize risks of pressure ulcers, and maximal maneuverability and stability. For people with money or generous insurance coverage, countless options exist. However, inexpensive and suboptimal models are all some people can afford. Many, such as Tom, end up using equipment left behind by others and likely inadequate to their needs.

Numerous types of wheeled mobility aids are now available. Different models generally fall into one of four categories: manual wheelchairs, in which the user is either pushed from behind or provides all the propulsive power, made from standard or ultra-lightweight materials; new power assist wheelchairs, which are basically manual models with a switch that temporarily turns on power, boosting the propulsion of the wheels as the user pushes; four-wheel power (battery-powered) wheelchairs, with a wide range of different controls (e.g., a joystick on the armrest, controls operated by the user's mouth, chin, head, or breaths) and features (e.g., tilt-in-space, recline, and power leg elevation in complex rehab wheelchairs); and three- or four-wheeled scooters, in which users sit in a captain's chair, affixed to a platform and positioned behind the controls. Although manual wheelchairs seem optimal for maximizing the physical fitness of persons who can use them, long-term self-propulsion can cause rotator cuff injuries, carpal tunnel syndrome, and shoulder pain. Careful evaluation by specialists, preferably in a seating clinic, is essential to ensure choice of equipment that maximizes independent function and minimizes physical risks.

> Tom does not have the upper body strength to self-propel a wheelchair for any distance and seeks coverage for a power wheelchair from Medicare.

DEALING WITH MEDICARE AND OTHER INSURERS

Medicare and other insurers typically will not pay for items or services unless they are deemed "medically necessary" (Box 42-2). Insurers often reduce the arguments to a simple question: Is the item or service medically necessary to treat a disease, disorder, or injury or is it primarily desired for convenience? This question poses a vexing problem for mobility aids, which by definition are not "treating" a condition but are explicitly recognizing that a permanent deficit might exist. Medicare adds to their evaluation the "in-home" rule: Items are covered only if persons must use them in their home. In Tom's case, he "furniture surfs" at home and uses the wheelchair only outdoors to travel longer distances; therefore, Medicare would view a power chair as a "convenience item" and deny Tom's request. Note that Medicare pays only for equipment that is needed within the patient's house. Medicare documentation requirements change periodically. Therefore, clinicians should be aware of current requirements when making a request for Medicare coverage of mobility aids.

Box 42-2. Tips on Documentation for Insurance Letters

Be specific and include all relevant information:

1. Diagnoses that lead to impairment.
2. Documentation of physical limitations, including impact on daily functioning.
3. Specific description of equipment and how it is used: what activities were limited; when and where will equipment be used.
4. Clear rationale justifying benefits

> Tom initially refused to use a cane, worried about how people would see him. Later Tom said, "I won't be seen dead in a wheelchair." Now Tom finds the wheelchair improves his independence.

A lingering sense of social stigma and other complex emotions often make people reluctant to use mobility aids. Primary care physicians may wish to work closely with rehabilitation specialists to find the optimal options for individual patients. When patients like Tom hesitate to use equipment that could potentially improve their safety, physicians should avoid "all-or-nothing" recommendations. Many patients successfully and appropriately use mobility aids intermittently. For example, Tom successfully "furniture surfs" at home but would benefit from using his cane outdoors or when in large crowds. Physicians should take care to avoid "all-or-nothing" declarations, making it clear that patients may use equipment in different ways at different times. In addition, physicians should help reframe issues for patients, emphasizing the ways in which aids will increase mobility for patients, rather than serving as an indicator of debility.

BLINDNESS AND LOW VISION

> Lorna, in her late 40s, has many medical problems, especially diabetes, which has limited her vision.

About 1.3 million Americans, roughly 5 in 1000 persons, are legally blind (central visual acuity of [20/200 in the better eye with correction or a field of vision of 20 degrees]), although about 80% of them have some useful vision.[11] Blindness does not mean total loss of vision; many blind people can still see shadows, light, colors, or images, albeit sometimes within extremely narrowed visual fields. Many others have low vision not fully corrected by eyeglasses. Vision problems can compromise mobility and activities of daily living, heighten risks of falls, and contribute to depressed mood. However, new technologies

and consumer products, such as computer screen readers, books on tape, and "talking" appliances, have dramatically expanded options and quality of life for many persons with impaired vision. When glasses, medications, or surgery cannot restore vision, focusing on making the most of the remaining vision to maintain independence is crucial.

> Lorna comes to the clinic for a routine visit, using a white cane to assist independent ambulation.

Office staff and clinicians should be trained about communicating appropriately with persons who are blind or have low vision. Introducing oneself and asking what kind of assistance persons might want are the first steps. At the front desk, persons may need assistance completing routine paperwork. Finding a private place to give this assistance is essential to protect patients' privacy. Offering to assist persons in getting around facilities is appropriate, but let the person make the first move. Persons who are blind typically use several strategies to navigate spaces: lightly holding the arm, just above the elbow, of a sighted guide, or proceeding independently with a white cane or guide dog and following a sighted guide who walks a few steps ahead. The ADA requires public and private facilities to allow service animals, such as guide dogs, on the premises even if pets are excluded. Facilities should have Braille and raised print signage marking doors and passageways so that persons can get around independently, should they choose.

Blindness or low vision may not be the person's chief complaint. Physicians should therefore not automatically assume that vision should be the first topic discussed. For patients such as Lorna, who has diabetes, physicians obviously should routinely question them about their vision and refer them to appropriate specialists. Limited evidence supports the value of routine questioning about visual functioning during primary care visits for all patients. However, depending on the clinical context, questions about sight may identify important problems. Useful questions include asking persons whether (with their glasses) they have trouble driving at night, seeing someone across the street, reading a newspaper, seeing details on the television screen, or going up stairs.

> Lorna lives alone. She would like a glucose monitor that would allow her to test her blood sugars at home. However, she reports trouble distinguishing her many different pill bottles.

Lorna's independence should not come as a surprise. Persons who become blind or develop low vision can continue living productive and independent lives. Rehabilitation programs specifically targeting vision loss can train persons in independent ambulation (e.g., using a white cane), in Braille (a system using raised dots to represent letters, numbers, punctuation, and certain words), and various assistive technologies to assist reading, writing, and other activities. As persons begin losing vision, large print materials (i.e., 14-point font or larger) can allow them to read printed materials, such as prescription labels on pill bottles or medication instructions. With more impaired vision, other devices (e.g., CCTV video magnifiers) may help, and new technologies may provide further assistance in the future. Health insurance usually will not pay for assistive devices for enhancing vision, although some Medicaid programs might pay for prescription eyeglasses. However, Medicare and other insurers now typically pay for selected health-related items such as home glucose monitors that "talk" (i.e., convey information orally).

Web sites such as those sponsored by the American Foundation for the Blind (www.afb.org) and National Federation of the Blind (www.nfb.org) offer extensive listings of various products and services to assist persons with visual disabilities. Some large health plans offer telephone information hotlines that provide recorded messages containing general information about health problems or conditions. Web sites designed to be accessible to all users, such as those of agencies within the US Department of Health and Human Services, offer growing volumes of accessible health information.

Unfortunately, clinicians rarely provide information in accessible formats, such as prescription drug or postdischarge instructions, test results, or appointment slips. At home, patients can sometimes use technologies to access this information, for example, by magnifying print many-fold using video magnifiers or closed circuit television systems. However, depending on individual preferences, giving patients information in large print, Braille, audiotape, or disability accessible digital formats (e.g., sending appointment reminders, test results, and other information through secure Internet portals) could readily improve the accessibility of information. If high-tech formats are unavailable, clinicians should discuss with patients who are blind or have low vision alternative ways of conveying critical information even by such low-tech means as telephone calls (e.g., to make sure patients understand medication instructions and provide visit reminders, see Box 42-3).

Other adaptive devices are critically helpful, albeit sometimes expensive. Synthetic speech systems (a synthesizer that does the speaking and a screen reader that tells the synthesizer what to say) allow persons with visual disabilities to "hear" texts that appear on computer screens. Text-to-speech software contains all the phonemes and grammatic rules of the designated language, producing

Box 42-3. Tips for Helping Patients Who Are Blind or Have Low Vision Manage Their Medications

- Record all pertinent information about their medications in a form useful for them: Braille, large print, audiocassette.
- Ask pharmacist to dispense medications of similar shape in different sized bottles to help differentiate and keep this consistent.
- Wrap rubber bands or other tactile clues around the bottle corresponding to the number of times a day they are to take that medication. Remove one band with each dose. At the end of the day, replace all bands for the next day.

fairly natural pronunciations. Keyboard commands instruct these systems to perform various functions, such as reading specific portions of texts, identifying the cursor location, and finding strings of text.

Optical character recognition technologies scan printed texts then speak the words using synthetic speech or save it on a computer. Technology that conveys graphic or pictorial information into accessible formats for persons with impaired vision remains limited. Nonetheless, current optical character recognition programs contain logic to identify and correct errors, such as major grammatic or spelling mistakes, before speaking the texts. For persons with low vision who can see enlarged images, screen magnification programs offer access without speech, although users can focus only on one part of the screen at a time. New technologies are being developed that address some of these concerns, but challenges remain to improving access to online or printed materials for persons with impaired vision.[4]

DEAF AND HARD OF HEARING

> Jerry, an auto mechanic in his early 50s and father of four, is growing increasingly hard of hearing. His children are frustrated that he will not admit and "deal with" his hearing loss.

Roughly, 9% of Americans have hearing loss, 10% of them with profound deficits. Age-related hearing loss (presbycusis) is the most common cause. At birth, 1 in 1000 children have severe to profound hearing loss, with four to five children having hearing deficits that impair verbal communication. Persons who are deafened prelingually (before the onset of speech, usually at the age of 3 years) typically have different communication patterns and preferences than postlingually deafened individuals, such as Jerry. In the former group, those who attend Deaf schools and interact with others through sign language often develop a strong cultural identity. In contrast, persons such as Jerry can feel that "going deaf" is embarrassing or an inevitable sign of aging and refuse to admit progressive impairments. Often, they feel isolated and lonely.

Tip on language: Persons who are "deaf" or "hard of hearing" generally prefer these terms to other labels. Many view such phrases as "hearing impaired" as well intentioned but inappropriate, because they imply that hearing loss requires cure. Phrases such as "deaf and dumb" or "deaf and mute" are offensive. When spelled with a capital D, Deaf represents a cultural or linguistic view of deafness, an understanding of deafness not as an impairment but rather as a cultural identity.

ASSISTIVE DEVICES

> Jerry's children convince him to get a hearing aid, although his health insurance does not cover it. However, he rarely wears the hearing aid because he feels it does not work.

Depending on the nature of the hearing impairment, some persons may find individual mechanical interventions useful.

Hearing Aids

Hearing aids aim to amplify sounds, with different settings to target sounds within particular wavelengths, depending on the person's needs and physical setting (e.g., quiet rooms for private conversations, settings with significant background noise). Hearing aids range widely in their prices, quality, and capabilities. Health insurance rarely covers these devices (Medicare explicitly does not cover them), so persons' financial resources largely determine the type of device they can obtain. Persons seeking hearing aids should undergo careful assessments by audiologists skilled specifically in these devices, and they must recognize that months of trial and error may ensue before they figure out how to make the hearing aid work well for them. Not surprisingly, because of these complexities, many people use their devices only intermittently and some abandon them altogether.

Assistive Listening Devices

Assistive listening devices (ALDs) aim to improve the "signal-to-noise ratio," thus allowing listeners to hear better. The process is technically equivalent to putting listeners' ears closer to the sound source. ALDs come in different types depending on their mechanisms for enhancing sound. These technologies are widely used in public settings, such as theaters and concert halls.

Personal amplified ALDs represent the most basic technology, consisting of a pocket-sized, lightweight amplifier with a microphone, either attached to the unit or connected by a wire. During conversations, users place the microphone near the speaker's mouth and hear the amplified sounds via earphones or headphones. Having one or more ALD units available in a clinic could assist people with hearing loss and may be acceptable even to patients who generally hesitate to admit difficulty hearing.

Cochlear Implants

Persons with sensorineural hearing losses, regardless of when they occur, can find that cochlear implants restore much of their hearing. Hair cells of the cochlea, positioned in the inner ears, normally transmit sounds to the brain. With a cochlear implant, sounds picked up by an external microphone are transmitted to electrodes that stimulate remaining nerve cells in the cochlea, which are then recognized by the brain as sounds. Experiences with cochlear implants are highly variable and the technology is very controversial, especially among Deaf parents who wish their deaf children to be raised entirely in the Deaf culture they themselves inhabit.

Telecommunications Technologies

Many devices are available to assist persons with hearing impairments, such as those displayed in Web sites sponsored by the Gallaudet University Technology Access Program (tap.gallaudet.edu) and Self Help for Hard of Hearing People (www.shhh.org). Examples of useful devices include vibrator beepers or watches, flashing lights to indicate ringing telephones or emergency alarms, amplified headsets for telephones, baby monitors that vibrate the parent's bed, closed captioning decoders on television sets, and telecommunications equipment and services. Communications technologies are advancing rapidly, perhaps in the future supplanting older modalities.

Teletypewriter

The teletypewriter (TTY), also called a telecommunications device for the Deaf, is a keyboard with an alphanumeric displays that, when linked through a telephone outlet or appropriately configured computer, can communicate directly with another TTY. TTY users then type their messages back and forth, often using shorthand phrases. ADA regulations require installation of TTYs in specified settings within health-care facilities. TTYs come in portable, lightweight models that some persons carry with them and simply plug into available telephone outlets. However, the widespread availability of smart phones and use of text messaging and other instant communication modalities is quickly making the TTY somewhat obsolete. The price of smart phones and monthly fees can pose a barrier to their use.

Telephone Relay Services

Anyone with a telephone or TTY can use telephone relay services (TRS), which by law are available free at all times under Title IV of the ADA. Dialing 7-1-1 nationwide connects directly to the local TRS, which uses operators called "communications assistants," to facilitate telephone calls for people who have difficulty hearing or speaking. A TTY user types a message that the communications assistant then reads aloud to a hearing person who answers the telephone. The hearing person speaks a return message to the communications assistant, who types this response to the TTY user. Some regions offer video relay services, in which a Deaf caller signs to the communications assistant with the use of video equipment (e.g., computer cameras with broadband connections); the communications assistant voices what is signed to the called hearing person; and then signs back the spoken response to the Deaf caller.

COMMUNICATION APPROACHES

People like Jerry, who lose their hearing later in life, typically have speaking skills comparable to persons who are not hard of hearing. However, the communication skills of prelingually or early deafened individuals depend very much on their early education. Methods for teaching deaf children have generated considerable controversy for well over a century, with some educators advocating completely "oral" approaches (i.e., forcing children to learn speech and lip reading, precluding use of visual or sign languages). Today, although deaf children might start with sign language training, many go on to "total communication" or "bilingual-bicultural" training, learning both sign languages (which do not have written forms) and spoken and written languages, such as English.

American Sign Language

ASL, used by approximately 500,000 Americans, is a unique language grammatically and linguistically distinct from English; it is not simply English translated into hand signals. Instead, ASL uses hand signals, facial expressions, and body movements to convey concepts as effectively as spoken languages. When persons who started life using ASL later learn a spoken and written language, typically English, their English knowledge is frequently comparable to that of others for whom English is their second language. In other words, they may have limited vocabulary, perhaps making note writing with their clinicians an ineffective strategy for communication. Importantly, sign languages vary from country to country. British sign language, for instance, differs fundamentally from ASL.

Lip (Speech) Reading

Many deaf and hard of hearing individuals rely, at least in part, on lip or speech reading. Someone such as Jerry,

Box 42-4. Important Questions When Taking a Hearing History.

- Age at onset (prelingually versus postlingually)
- Preferred language, communication modality (e.g., sign language, lip reading, English using assistive device)
- Cultural identification
- Educational history, including level of understanding of spoken and written English

who lived his life speaking English, typically finds lip reading easier than someone whose first language is ASL. Lip reading is inevitably imperfect. Only about 30% of English words are clearly readable on the lips, because many English words form at the back of the throat. Therefore, people who rely on lip reading may not necessarily know when they misunderstand or misinterpret spoken words.

Primary care clinicians receive little training about the diversity of experiences faced by persons who are deaf or hard of hearing and strategies to overcome communication barriers (see Box 42-4). The limited training generally focuses on pathology of hearing loss. Therefore, clinicians can carry erroneous assumptions about methods for communicating effectively with persons with hearing disabilities. For instance, they may believe that note writing and lip reading provide effective communication, but in many instances, they do not (see Box 42-5).

COMMUNICATION ACCOMMODATIONS

> Judy's doctor did not have an ASL interpreter during her first Pap test, so she did not understand the procedure. She felt so traumatized that she refuses to have another Pap test.

The ADA requires accommodations to ensure effective communication, unless doing so would cause significant difficulty or expense. The law stipulates that patients' preferences for communication accommodations should receive primary consideration. However, the clinicians have the final authority to determine what constitutes effective communication.

However, many people need additional communication accommodations, such as a sign language interpreter. The ADA does not require health insurers to cover sign language interpreter costs, and it prohibits providers from charging patients for this expense. Sometimes, sign language interpreter fees can exceed health insurance reimbursement for the visit, posing a financial disincentive for clinicians to hire interpreters. Nevertheless, legal experts caution physicians against using ineffective communication strategies. Courts have held physicians legally liable for failing to accommodate communication needs, especially when medical injury ensues.

Box 42-5. Accommodations to Ensure Effective Communication

- Facing the person while speaking
- Keeping the mouth visible
- Speaking naturally but clearly, without shouting or rushing
- Ensuring adequate lighting, especially of the face
- Eliminating background noise
- When clinicians must wear surgical masks, choosing clear or transparent fog-free masks could assist lip readers

NEED FOR ACCESSIBLE EQUIPMENT

> Angela had a high thoracic spinal cord injury in her teens. Now in her late 20s, she is married and thinking of having a child.

Since her injury, Angela has not been weighed, and she has not had a complete physical examination, including a Pap smear, by her primary care physician. Her physician's office has neither a wheelchair accessible scale nor an examining table that lowers automatically to wheelchair height for easy transfer. No one feels comfortable lifting Angela out of her wheelchair onto the fixed-height examining table, designed for the convenience of a standing clinician. Once she becomes pregnant, following her weight and conducting comprehensive physical examinations will become even more important. Regulations relating to the ADA Titles II and III stipulate certain requirements for accessibility to public and private structures, but they say nothing about equipment or furnishings. The law requires that persons with disabilities receive equal services as those without disabilities, but does not specify exactly how to achieve that goal.

Access problems in health-care settings are readily apparent. For instance, when Judy, who is deaf, goes in for radiologic procedures, she will not hear spoken instructions from the radiologist or technician, who is often positioned behind opaque radiation shields. Lorna, who is blind, will not be able to see the instructional video in the mammography center waiting room. Tom, with his foot drop and propensity to fall, may find lengthy hospital corridors hazardous without railings along the walls. Angela even has trouble getting into her physician's office, because the heavy plate glass door has no automatic opener.

The U.S. Department of Justice Disability Rights Section and the U.S. Department of Health and Human Services Office of Civil Right have provided technical assistance recommendations for ensuring the accessibility of health-care facilities to individuals with mobility disabilities.[5] The U.S. Access Board has promulgated standards for ensuring that the built environment and fixed structures are physically accessible; these standards also govern health-care facilities, including hospitals and private clinical offices. However, no laws or regulations had stipulated accessibility standards for medical diagnostic equipment, including examination tables, weight scales, and imaging equipment.

To address this need, Section 4203 of the 2010 Patient Protection and Affordable Care Act (PL 111-148) amends Title V of the Rehabilitation Act to require the U.S. Access Board, in consultation with the Food and Drug Administration, to issue technical standards for accessibility of medical diagnostic equipment for adults with disabilities. The statute explicitly aims for standards that will allow adults with disabilities to use equipment as independently as possible. The law explicitly envisions design features that permit individuals with disabilities to safely transfer onto diagnostic equipment, such as exam tables, with minimal assistance from others. The U.S. Access Board is currently considering a variety of accessibility standards that would apply to examination tables and chairs, stretchers, diagnostic imaging equipment, mammography machines, and weight scales.[6] After rules on accessibility standards are promulgated, the U.S. Department of Justice will determine how widely they apply throughout the health-care delivery system. Thus, over the next decade, legal requirements may further support expanding the accessibility of health-care facilities to individuals with disabilities.

- Never make assumptions about the abilities, preferences, or expectations of persons with disabilities: Ask how you may assist them and, as much as possible, comply with their wishes.
- Disability marks an interaction between a person's functional abilities and the environmental demands placed on them.
- Disability can be lessened by modifications in the environment.
- Many assistive devices and adaptive technologies exist to eliminate the gap between functional ability and environmental demands.
- Physical therapists, occupational therapists, and physiatrists are important resources for both providers and patients. Clinicians should make appropriate referrals.
- Health-care providers should seek to alter their practice environment to make it accessible to persons with disabilities by eliminating physical and communication barriers.

The Disability Process

Understand the steps:

- A patient initiates a claim by filing with the Social Security Office.
- The state-based Disability Determination Service (DDS) gathers evidence to support claims of disability. They will request records of previous clinic visits and hospitalizations. They can request medical evaluation either from the treating physician or from a physician consultant who contracts with the SSA.
- A board consisting of medical and nonmedical personnel at the DDS reviews the full application, including the medical documentation. Approximately 30% receive SSDI at this stage. If not approved, the applicant can appeal within 60 days. Approximately 15% of denied claims are reversed at this stage. If still denied, applicants can appeal to an administrative law judge; new information can be included and the applicant can have a lawyer. Approximately one half of denials are reversed at this stage.

Concepts:

- Clinicians are not expected to decide whether or not the patient is disabled; rather they are to provide information regarding the impairment.
- Clinicians can familiarize themselves with the "Disability Evaluation Under Social Security," also known as the "Blue Book," which lists the medical criteria that the SSA uses to determine impairment and disability for common causes (available online at www.ssa.gov).
- Referral to lawyers or advocates can help patients.

Writing the letter: The letter should detail the following:

- Duration of impairment
- How the impairment affects ability to work and function
  - —Be detailed and give specific examples
  - —Include functional, sensory, emotional, and cognitive examples:

    Mrs. B cannot be expected to lift more than 10 pounds or walk further than 15 feet.

    During his last manic episode, Mr. B drove the delivery truck to Mexico and did not return it.
  - —Include documenting evidence: diagnostic tests, radiographs, laboratory, or functional testing
  - —Expected duration of impairment
  - —Likelihood of recovery

DISCUSSION QUESTIONS

1. What is a disability?
2. Name three examples of assistive devices for persons with lower extremity mobility impairments, hearing loss, or low vision.
3. What steps can clinicians take to make their offices more accessible to persons with sensorimotor disabilities?

4. What is ASL? How does one use an ASL interpreter?
5. What are key components for insurance documentation of a mobility aid?

RESOURCES

American Foundation for the Blind. http://www.afb.org.

Gallaudet University Technology Access Program. http://tap.gallaudet.edu.

Self Help for Hard of Hearing People. http://www.shhh.org.

National Federation of the Blind. http://www.nfb.org.

7-1-1 nationwide connects directly to the local TRS, which uses operators called "communications assistants" (CAs), to facilitate telephone calls for people who have difficulty hearing or speaking.

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Chapter 43

HIV/AIDS: Impact on Vulnerable Populations

Ronald H. Goldschmidt, MD, Joanna Eveland, MD, and Jacqueline P. Tulsky, MD

Objectives

- Describe the current state of HIV among underserved and vulnerable populations in the United States.
- Understand the importance of testing, diagnosing, linking to and retaining in care, and managing HIV along all stages of the HIV care continuum.
- Review groups at highest risk for morbidity and mortality of HIV/AIDS.
- Describe challenges to patient care including patient, provider, system, and disease factors.
- Identify interventions to improve HIV prevention efforts.
- Identify interventions to improve care for vulnerable patients with HIV or AIDS.

INTRODUCTION

Don Sloan is a 34-year-old recently unemployed truck driver who is brought to the emergency department following an alcohol-related automobile collision. No serious traumatic injuries are found and he is medically stable. Prior to discharge he is informed of the laboratory test results, including an HIV test he had been told would be done as part of routine testing unless he refused. The emergency department attending tells him his HIV test is positive, orders a confirmatory HIV test, and refers Mr. Sloan to the outpatient HIV clinic.

Major advances in treating human immunodeficiency virus (HIV) have shifted HIV from a terminal illness to a manageable chronic disease. The collaborative efforts of patients, advocates, and the medical community have rapidly advanced access to highly effective treatment. Consequently, individuals who learn they are HIV infected and take antiretroviral drugs (ARVs) daily have excellent health outcomes and a low risk of passing HIV to others. Globally, however, HIV is still the world's leading killer due to an infection.

In the United States, HIV/AIDS is still found disproportionately among people of color, especially African Americans and Latinos, men who have sex with men (MSM), injection drug users (IDUs), those with mental illness, and the poor. New infections continue to occur at alarming rates, especially among young MSM of color. Disparities in new infections and in care characterize the global epidemic as well, with gender inequity driving the growth of infections in women and girls.

This chapter reviews critical elements of prevention and treatment of HIV/AIDS, including strategies for improving care for vulnerable populations with a focus on populations in the United States.

THE HIV CARE CONTINUUM

The causes of HIV infection have not changed significantly since it was first reported in the early 1980s. HIV is primarily transmitted through sexual exposure, injection

drug use, and less commonly through mother-to-child transmission (especially in the United States). Persons with HIV infection may be asymptomatic and unaware of their infection for many years. However, a person infected with HIV can transmit the infection from the time he or she becomes infected. Medications that effectively suppress viral load (the amount of HIV virus circulating in the bloodstream) can significantly decrease and possibly eliminate infectivity.[1] Suppressing the virus therefore both treats the disease in an individual and prevents disease transmission to others.

STRATEGY TO ADDRESS THE HIV/AIDS EPIDEMIC

The global community proposed a series of goals and targets to achieve a vision of zero new HIV infections, zero AIDS-related deaths, and zero discrimination in a world where people living with HIV are able to live long, healthy lives. In 2010, for the first time, the US government developed a national HIV/AIDS strategy to address the HIV/AIDS epidemic and achieve an HIV-free future. The three primary goals include reducing the number of people who become infected with HIV, increasing access to care and improving health outcomes for people living with HIV, and reducing HIV-related health disparities.[2] Those working on targets for the global HIV epidemic have similar goals. United Nations Programme on HIV/AIDS (UNAIDS) has proposed a 90/90/90 target by 2020, in which 90% of all people living with HIV know their diagnosis, 90% are in treatment, and 90% have viral suppression. Disease modeling predicts that if these goals were achieved, by 2030 HIV would no longer be an epidemic disease.[3] The World Health Organization is also focusing on key marginalized and vulnerable populations at highest risk as an essential strategy to eradicate the disease.

GAPS IN HIV/AIDS CARE

Although the advances in HIV diagnosis and treatment over the past few decades have been spectacular, the reality of HIV care falls far short. Nineteen million of the 35 million people infected with HIV globally do not know they are infected.[3] In the United States, only 28% of persons infected with HIV have an undetectable viral load, the gold standard of HIV care.[4,5] In contrast, some countries with more limited resources have achieved higher rates of viral suppression through coordinated systems of care. Critical gaps in diagnosing, linking to care, and treating persons with HIV apply across all segments of the US population, not only the underserved and vulnerable. But there is no question the gaps apply disproportionately to those who are not consistently engaged with the health-care system. Substance use disorders, mental illness, poverty, stigma, and other barriers to accessing ongoing health-care contribute substantially to less than ideal care and perpetuate continued HIV transmission.

GARDNER CASCADE (HIV CARE CONTINUUM)

The representation of these successes and deficits in diagnosis, linkage, and retention in care and successful treatment is best described in the Gardner Cascade,[4] also called the HIV care continuum (Figure 43-1). Used by health-care agencies throughout the world to monitor outcomes in HIV care initiatives, the HIV continuum recognizes that there are multiple stages during a person's HIV diagnosis and treatment that provide opportunities and challenges to optimal care.

The cascade defines five main steps to achieving optimal treatment: diagnosis, linkage to care, ongoing care, receipt of appropriate antiviral medications, and achieving viral suppression. At each of these stages, there is a decrement in those proceeding to the next step toward viral suppression. In the United States, only 80% of those with HIV know of their diagnosis, only 66% are linked with care, only 40% retained in care, only 30% start on ARVs, and only 28% achieve actual viral suppression. That Rwanda, Mexico, and Brazil have been able to achieve viral suppression in about 80% of those on medications proves better control is possible.[3]

Every interaction with clinicians, social services, community programs, and patients can be an opportunity to improve engagement in the continuum of care. Targeted interventions for persons at risk for or living with HIV/AIDS that provide housing, peer support, and culturally sensitive programs have been shown to bridge the linkage and retention gap.[6] Once retained in care, most will receive antiretroviral therapy, but only a percentage of them will remain well controlled on treatment. The development of drug resistance, inconsistent access to medications, and poor adherence all contribute to lack of viral suppression.

Poor adherence in itself has a multitude of causes. For example, in some communities, HIV stigma and barriers to disclosing one's HIV status to partners may decrease medication use. In a study reported at the 20th International AIDS Conference, providing counseling that supported disclosure within a person's relationship led to improved adherence to medications and viral suppression rates.[7]

EPIDEMIOLOGY OF HIV AND AIDS ALONG THE CONTINUUM OF CARE IN THE UNITED STATES

In 2011, approximately 1.2 million persons were living with HIV/AIDS in the United States, including 180,900 who were undiagnosed and unaware of their HIV

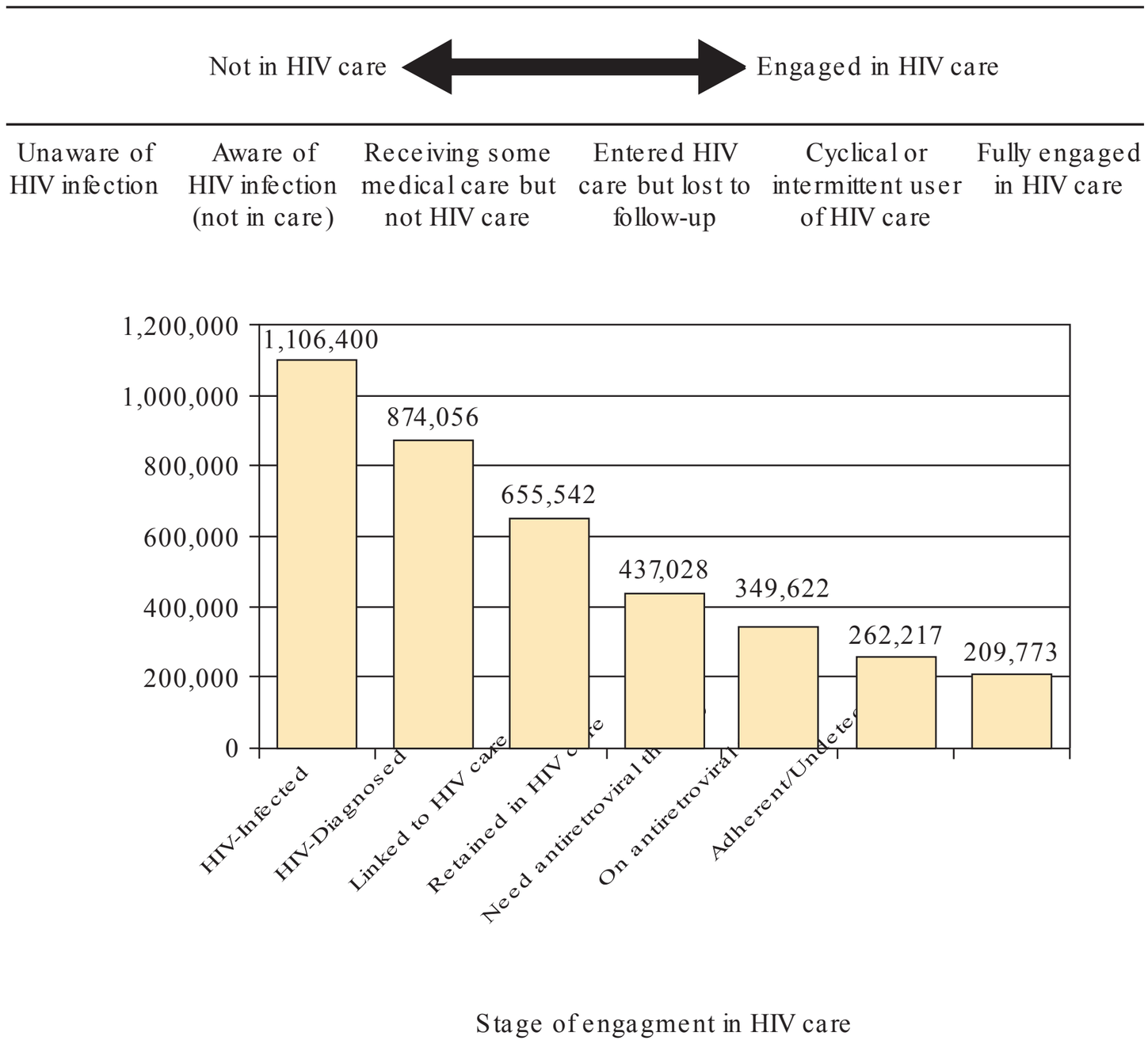


Figure 43-1. The HIV Care Continuum in the United States. A: Description of the spectrum of engagement in HIV care (Health Resources and Services Administration [HRSA] continuum of HIV care). B: Quantification of the engagement in HIV care in the United States spanning from HIV acquisition to full engagement in care, receipt of antiretroviral therapy, and achievement of complete viral suppression. (From McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clin Infect Dis 2011;52:793-800.)

infection. New infections occur in nearly 50,000 persons a year with 32,000 being diagnosed with advanced immune suppression or AIDS.[8] Prevention of transmission and earlier diagnosis are imperative to achieving an HIV/AIDS-free future.

PREVENTION AND CARE CONTINUUM IN MEN WHO HAVE SEX WITH MEN

Gay, bisexual, transgender, and other MSM of all races and ethnicities remain the population most affected by HIV in the United States. The impact of HIV in the MSM population is underscored by reports that while 4% of the male population is MSM, more than 75% of new HIV infections among males were in MSM.[8]

Prevention of transmission in MSM is therefore key to eradicating HIV in the United States. The mainstay of prevention in this population has been sexual risk reduction. Though condom use remains key to stopping the spread of HIV in the United States, adjuvant measures such as techniques to recognize riskier situations and medications to reduce transmission are emerging. Condoms used consistently for anal sex can stop more than 70% of new HIV infections.[9] While condom availability has increased significantly, access for some at-risk populations such as youth and incarcerated persons may still be a limiting factor. Many studies suggest 100% condom use is rare and rates of condom use, the most important prevention tool, are declining in this population. Fortunately, because large numbers of MSM are receiving effective antiretroviral therapy and therefore have low viral loads, transmission to their partners, even in the absence of effective barrier protection, is reduced.

Medical male circumcisions reduces the risk of heterosexually acquired HIV infection in men by approximately 60% and is a key intervention globally in settings with high HIV prevalence and low male circumcision rates, but has not been shown to reduce MSM transmission.[10]

Home rapid testing also holds great promise for MSM. A study of high-risk MSM in New York showed that ready access to rapid test kits allowed introduction of testing to unknown partners before sexual activity, resulting in no episodes of high-risk sex with known HIV-infected partners.[11]

Another method of prevention is the use of postexposure prophylaxis (PEP) or a course of antiviral medication started within 72 hours after an exposure to HIV. First shown to significantly reduce HIV transmission in exposed health-care personnel, this strategy is now used for those with other exposures as well.[12] In underserved communities, unfortunately, many people at risk of acquiring HIV are unaware of this method of risk reduction and may not recognize situations during which they are at high risk. Timely access to care, medication availability, cost, and adherence to the 28-day treatment course are other barriers to use of PEP in underserved patients.

Pre-exposure prophylaxis (PrEP) is another powerful technique to prevent infection for HIV-negative persons at ongoing risk for HIV infection, MSM with multiple partners, and IDUs, for example. A daily dose of an ARV regimen in these high-risk patients may reduce the chance of acquiring HIV by up to 92%.[13] Extensive counseling regarding prevention, adherence, and benefits and risks is critical, as effectiveness is closely tied to adherence.[14] Treatment with a once daily single pill combination of two drugs, tenofovir and emtricitabine, should be considered for HIV-uninfected MSM, heterosexuals, and IDUs at risk for HIV infection, including those in serodiscordant relationships. Patients receiving PrEP must be HIV negative and hepatitis B status must be taken into consideration at the onset of care. Regular examinations for drug toxicity, sexually transmitted diseases, and careful surveillance for newly acquired HIV infection must follow. Daily PrEP is expensive but patient assistance programs for high deductible, low benefit, or uninsured persons are available.

PREVENTION AND CARE CONTINUUM FOR RACIAL AND ETHNIC MINORITIES

The racial disparities in HIV infections continue to be glaring. Blacks account for 44% of new infections but are only 12% of the US population. Hispanic/Latino populations were diagnosed with 21% of new HIV infections, but are 16% of the population.[15]

The risk of HIV acquisition is higher for black MSM, despite studies reporting that they use condoms at similar rates as white MSM.[16] Lack of access to care, incarceration, and selection of other black MSM as sexual partners have been demonstrated to contribute to this ongoing risk. With a higher prevalence of HIV infection in this community, the chance of HIV increases, even for those with lower risk behaviors.[17]

Among Latinos, MSM are also disproportionally affected. Language and immigration status may be additional barriers to linkage to care and successful treatment. A study of undocumented HIV-positive Latino immigrants in Texas found that they presented later to care than their White counterparts, though once engaged in care had similar outcomes.[18]

Recognition of HIV risk and disclosure of HIV status are major barriers to HIV prevention and care in minority communities. Effective prevention messaging must occur in community settings in order to reach individuals who may engage in high-risk behaviors, but do not identify as part of a high-risk group. Faith-based outreach programs that offer HIV testing in African American churches are one innovative outreach model.[19] Interventions that are skill based (rather than didactic), culturally targeted, and use peers have been found to be most effective.[20]

PREVENTION AND CARE CONTINUUM FOR WOMEN

Women now comprise about 20% of those diagnosed with HIV/AIDS in the United States (see Chapter 34). Black women accounted for 13% of all new HIV infections in the United States in 2010 and nearly two-thirds (64%) of all new infections among women.[8]

Women overwhelmingly are infected through heterosexual contact. Women often have limited knowledge about their partner's risk factors for HIV/AIDS and often have the misperception that they are at low risk of contracting AIDS. This is especially true for minority women. Studies show that among MSM, African-American and Latino men are more likely to identify themselves as heterosexual and report having sex with women.[15] Women may not feel empowered to insist on safe sex practices. Fear of emotional or physical abuse or the withdrawal of financial support, as well as substance use, prevents some women from consistently using condoms. Intimate partner violence also has been associated with increased HIV risk (see Chapter 35).[21] A history of trauma and victimization is common in HIV-infected women (see Chapter 36).[22] Minority women also face a number of structural factors that contribute to women's vulnerability and place them at high risk for infection: high rates of incarceration among minority men, residential segregation and lack of medical services, and disapproval of homosexuality.

Women who desire pregnancy do not use condoms and may discover that they are infected only when they seek care for their pregnancy. Moreover, they are often unaware of measures to prevent HIV transmission despite insemination, especially sperm washing and PrEP. PrEP can be successful as a female-controlled prevention tool.[14] Successful models such as the Bay Area Perinatal AIDS Center exist for counseling serodiscordant couples on risk reduction and empowering them to make healthy decisions around fertility (link: http://aidsetc.org/directory/local/bay-area-perinatal-aids-center).

Perinatal prevention of mother-to-child transmission has been the biggest success story in HIV prevention.

HIV-positive women who receive successful antiretroviral treatment during pregnancy, antiretroviral medications in labor and delivery, and whose babies receive postpartum antiretroviral prophylaxis almost always have HIV-negative children. Globally, the goal of prevention of perinatal transmission seems achievable. In just 3 years, the numbers of infected women who were treated in lower- and middle-income countries jumped from 47% to 67%.[23] In the United States, a large percentage of the fewer than 200 babies born with HIV annually are from racial/ethnic minority mothers.[24]

PREVENTION AND CARE CONTINUUM FOR YOUTH

Adolescents and young adults face special challenges with respect to prevention, diagnosis, and linkage to care (see Chapter 21). Many do not recognize the need for or have easy access to the health-care system. Adolescents who are sexually active or experiment with drugs and alcohol are at high risk for acquiring HIV. This is especially true for displaced youth who have left home, often because of stigma around their identity, trauma in their home setting, or mental health reasons.

Young American MSM of color are at excessive risk of HIV. From 2002 to 2011, while many groups saw stable or declining rates of new HIV infections, rates increased by 133.5% in 13- to 24-year-olds, with most of these new infections occurring in young African-American and Latino MSM.[25] Peer social support appears to increase HIV testing rates for young African-American MSM.[26] Interventions utilizing social media and other Internet resources as well as text message–based outreach strategies have shown promise for reaching this vulnerable group.[27]

PREVENTION AND CARE CONTINUUM IN SUBSTANCE USERS

> The Positive Health Program at San Francisco General Hospital has incorporated access to buprenorphine therapy into HIV primary care for IDUs. Patients also have access to substance abuse treatment and harm reduction services. This multidisciplinary program has improved retention and engagement in care for opiate-dependent patients.

IDUs represented 8% of new HIV infections in the United States in 2010. Since the 1980s, HIV incidence among IDUs has decreased by nearly 80% through education and access to safer injection drug tools, such as clean needles.[28] The effect of substance use on the spread of HIV is not limited to sharing needles. Both the sexual partners and the children of intravenous drug users are at high risk for infection, as substance users are more likely to engage in high-risk behaviors such as multiple sexual partners, unprotected sex, exchanging sex for drugs, or using drugs to enhance the sexual experience. Use of crystal methamphetamine, "poppers," and even sildenafil (Viagra) or others have been associated with unprotected serodiscordant sex in MSM.[29] For those who are already infected, drug use also can adversely affect ARV adherence.

Public health strategies employing harm reduction approaches have had dramatic results in decreasing HIV and hepatitis transmission for IDUs. These include needle exchange, methadone maintenance programs, and buprenorphine and other substance use programs. Cities that created programs with outreach workers to facilitating legal access to sterile needles and linkage to drug treatment have been able to curtail the spread of disease. Nevertheless, needle exchanges or over-the-counter purchase of syringes remains illegal in some of the locations most affected by the epidemic. Legislation to allow retail pharmacies to sell insulin-type needles and syringes has further expanded easy access to sterile needles.[30]

Co-locating services for IDUs has been shown to have dramatic effects on HIV care, even in the face of ongoing substance use.[31] For example, care improves in clinics serving IUD patients that offer risk behavior education, or in drug treatment programs offering HIV testing and treatment, or when methadone clinics offer medication assistance for prevention (PrEP) and provide HIV antiretroviral treatment through directly observed therapy (DOT).

PREVENTION AND CARE CONTINUUM OF TRAUMATIZED AND MENTALLY ILL POPULATIONS

Trauma of all varieties can increase the likelihood of HIV infection (see Chapter 36). Indeed, history of trauma, sexual abuse, and victimization is common among persons with HIV/AIDS. Trauma-informed care has led to an increased awareness of the long-lasting and insidious effect of trauma early or later in life. People with histories of trauma engage in more risky behaviors, including ones that are self-destructive. Lack of trust in health care among traumatized patients can prevent opportunities for testing, early diagnosis, and engagement in care.[22]

Among individuals living with mental illness, the prevalence of HIV infection is dramatically increased when compared to the general population. The presence of mental illness also portends difficulty with treatment of this complex disease. Indeed, depression is remarkably common but underdiagnosed in patients with HIV. Treatment of depression may improve ability to adhere to medications.[32] Intermittent risk behaviors, lack of adherence

to prevention measures, and inattention to medical matters are common when mental illness is exacerbated.

PREVENTION AND CARE OF INCARCERATED PATIENTS

Many incarceration settings have high rates of HIV infection (see Chapter 27). One analysis found that because of the incarceration of drug-using and mentally ill persons, one in seven persons with HIV was discharged from a US prison or jail within the past year.[33] Recent literature suggests that the stigma of being identified as HIV infected is still a significant barrier to care for incarcerated persons.[34] Release from jail or prison is an especially vulnerable transition time; efforts to improve linkage have been adopted successfully with the help of ongoing studies.[35]

HIV TESTING

IMPORTANCE OF ROUTINE AND RISK-BASED TESTING

Without knowing their diagnosis, people cannot access treatment that can both be life-saving and decrease transmission to others. Those who know they are HIV positive have been shown to reduce their risk behavior. In addition, some strategies adopted by vulnerable individuals, such as serosorting by HIV-MSM (choosing to have unprotected sex with partners who report they are also HIV negative), actually increases the risk of acquiring HIV when greater than 20% of the community does not know their status.[36] Novel outreach strategies—such as mobile outreach to homeless youth, offering incentives for testing, and testing at needle exchanges—increase ease, and opportunities for testing may be required to expand diagnosis in people living in communities where the prevalence of infection, and therefore risk of transmitting or contracting HIV infection, is high.

TESTING STRATEGIES

Rapid HIV screening that allows for immediate disclosure of results may be particularly useful for people who may have difficulty returning for testing results. There are two principal approaches used in HIV testing: routine screening and risk-based testing.[2]

Routine Opt-Out Screening

Routine "opt-out" HIV testing, which can diagnose some of the currently undiagnosed persons, should be performed once for all persons regardless of risk. The US Preventive Services Task Force recommends one-time routine HIV screening for those between the ages of 15 and 64 years and the Centers for Diseases Control and Prevention (CDC) recommends one-time testing between 13 and 64 years old. Routine testing is independent of risk, akin to obtaining a complete blood count. The "opt-out" process informs the patient that HIV testing will be one of the routine laboratory tests performed unless the patient chooses not to be tested ("opts-out"). It is critical to inform patients when routine testing is to be performed and to allow them to "opt out" to avoid raising concerns based on suspicion of coercive or discriminatory treatment. The recommendation for routine screening is for one-time testing only; no additional routine testing is recommended. However, periodic risk assessments should be performed to determine if additional risk-based testing is needed.

Risk-Based Testing

Obtaining sexual history often is neglected or performed too infrequently to both diagnose new HIV (and other sexually transmitted diseases) or to provide an opening for discussing safer sex. A wide variety of culturally targeted tools and prompts, from patient-oriented educational materials in waiting rooms or on examination walls to clinician-oriented electronic reminders in the electronic medical record (EMR), have attempted to improve screening. Up to 33% of sexually active MSM have not had an HIV test in the past 1 year, underscoring the shortfalls in testing practices.

HOME TESTING

Numerous home HIV tests are available and can be extremely helpful in vulnerable populations that are not connected to care. However, false positives and false negatives occur, so the essential next steps of support for the patient, confirmatory testing, and linkage to care remain problematic. Demonstration studies have shown that encouraging MSM to utilize home testing with casual partners can be acceptable and find new HIV infections.[37,38]

SPECIAL CONSIDERATIONS IN PREVENTION—STIGMA AND HIV

Despite enormous evolution of society's understanding and acceptance of a broader range of sexuality, stigma continues to inhibit testing, disclosure, and care. Stigma affecting persons at risk for HIV because of their sexual orientation, race, poverty, education inequities, and substance use continues to increase the risks of contracting HIV and prevent diagnosis and treatment for HIV/AIDS. For many, accessing and remaining in care are fraught with isolation or fear, including fear of disclosure and loss of relationships, jobs, and housing if they are diagnosed with HIV or disclose they have HIV.[39] The challenge of

helping people overcome these fears remains an essential component in maximizing patient care across the care continuum.

Stigma also applies to commercial sex workers and transgendered people in the United States. Fear of disclosure of the diagnosis or prosecution for sex trade or illicit drug use can prevent some from seeking help. Programs with effective prevention measures, such as needle exchanges, over-the-counter purchase of syringes, and periodic testing and treatment of sexually transmitted diseases are sometimes avoided to prevent identifying the consumer of such services as possibly HIV infected.

Attitudes among and within the health-care system can also be stigmatizing. For example, many clinicians caring for patients with HIV hold negative attitudes toward IDUs and are less likely to start ARV treatment. Cultural competence programs aimed at reducing stigma that target providers at all levels and health-care sites and their communities can foster open and sensitive services, reducing the fears of people at risk for or with HIV.

ACCESS TO HIV/AIDS CARE: GENERAL PRINCIPLES

> After release from the emergency department, Don Sloan accepts help from one of the HIV counselors in disclosing his HIV status to one main and two casual partners. He is reluctant to start HIV medications, insisting to his new provider that he could get himself healthy without a "bunch of pills." His provider focuses on starting him on antiretroviral therapy. Reluctantly he accepts the prescriptions but then has trouble filling them at the pharmacy because insurance coverage requires special authorization. The out-of-pocket costs for the medications are prohibitively high. The pharmacy offers to contact his provider for authorization or cheaper alternatives, but Don tells them not to bother and misses his 1-month follow-up appointment.

Although inequities in HIV care remain for vulnerable populations, HIV/AIDS is unique in the range of resources available. In the United States, Medicaid coverage for prevention, clinical care, and many ancillary services is stronger than for many other diseases. Through federal and state programs and initiatives, such as the AIDS Drug Assistance Program (ADAP), patients with HIV/AIDS can receive timely clinical care and medications in most states. Some states may have waiting lists for the ADAP program, leading individuals to move to another state to obtain coverage. The federally funded Ryan White program covers ancillary services, such as case management, urgent entrance into care programs, and dental services for people living with HIV and AIDS. The Affordable Care Act (ACA) is making coverage available to many who could not access it previously. However, insurance alone does not mean care is available; for example, accessing HIV care providers or finding dental care in many states remains difficult.

CARE FOR VULNERABLE HIV PATIENTS: CHALLENGES AND APPROACHES FOR LINKING, RETAINING IN CARE AND VIRAL SUPPRESSION

> Maria Chavez is diagnosed with HIV infection on routine prenatal screening. Her physician and HIV health educator meet with her to explain HIV and the care recommended. She starts ARV therapy immediately. She is given the contact information of the counselor so that she can receive ongoing supportive care. She meets with a case manager who helps her identify transportation as a barrier to attending medical visit. She is provided with taxi vouchers. She is also referred to a peer support program for HIV-positive women. She returns in 3 days to see the health educator to re-discuss questions she has about the medications and safe practices for her and her baby, such as alternatives to breast feeding. Soon she has an undetectable HIV viral load and proceeds with a normal pregnancy. She delivers a healthy, HIV-negative baby and continues to adhere to her medications.

MULTIDISCIPLINARY TEAMS

The cornerstone of successful medical care for HIV patients is the formation of a system of care that addresses the multiple medical and social issues. Multidisciplinary teams operating with the primary goals of providing comprehensive patient-centered care that can address underlying social and economic concerns and integrate primary care with urgent and subspecialty care are becoming common in practices caring for persons with HIV. These systems of care can fill voids for vulnerable populations. Linking patients to community resources and entitlement services are key components of successful programs. Case management is an important tool in improving care of particularly high-risk patients.

New approaches throughout the health-care system are being developed to provide comprehensive coverage, control costs, and ensure all patients receive the best possible care. Changes such as same-day access, patient registries, attention to population health, multidisciplinary teams, incorporation of medication reminders, and prevention and management tools via the electronic medical record are examples of changes that are critical in providing care to the underserved and underrepresented.

> The Mission Neighborhood Health Center (MNHC), a community clinic serving low-income Latino patients in San Francisco, California, retains more than 90% of their

400 patients in regular HIV care through the use of both patient registry technology and a team-based care approach. Using a database linked to the Electronic Health Record, MNHC's retention coordinator generates a monthly list of patients who have fallen out of care. The multidisciplinary team regularly reviews the list and an individualized plan is then made to reengage each patient in care. For one patient, that means a call from the case manager to link him/her to a drug treatment program. For another patient, the outreach worker finds him/her underneath the bridge where he/she camps out. For a third patient, the community pharmacist is able to reconnect him/her to care when he/she came in for medications.

TREATMENT CHALLENGES

Advances in HIV treatment may help facilitate adherence. Many patients initiating HIV treatment have the option of regimens consisting of fixed dose combination pills taken once daily that are generally well tolerated.[40] Packaging medications in daily packets or labeled blister packs may help with adherence to treatment. Ongoing studies of text messaging reminders to take medications, health messages, and appointment reminders are examples of technological advances in supporting adherence and linkage to care (see Chapter 17).[41] Coordination with other clinical services, such as outreach services linked to methadone clinics, psychiatric care, housing, and nutrition services have become more widespread. Case management is now common and the role of supportive peers and professionals outside of the medical clinic regularly support adherence and overcome other obstacles.

COMMUNITY CHALLENGES

Addressing the local challenges in prevention and care in disparate communities should be individualized. The most successful prevention efforts are fueled by input and direction from affected community members and leaders.[42] Those who are infected and seeking screening need to know that their illness will not be judged and that they will receive patient-centered care that supports their self-efficacy. In tight-knit communities, a patient may be afraid to be seen in an HIV clinic; therefore, discretion is another hallmark of appropriate outreach and care. Safety from legal prosecution is a concern for undocumented immigrants, substance users, and sex workers. Increasingly, laws that criminalize transmission of HIV are recognized as obstacles to HIV testing, disclosure, and elimination of stigma.[43] Many communities have legal aid specifically expert in issues involving HIV. Drug use tends to be a community problem; community programs that help drug users engage in care despite continued drug use can be a critical component in establishing care for both HIV and drug addiction.

One approach to care has been to establish clinics that focus on a single community: Hispanics, African Americans, women, adolescents, or MSM. Women need to know that they will be sensitively cared for as well, as HIV-infected women may be intimidated by being in a predominantly male-serving clinic. Establishing clinic times when a critical mass of women can be seen while accommodating to child care issues lowers the barrier for engagement and retention in care. Clinics focusing on the care of families can integrate medical and social needs of all family members.[44]

CONCLUSION

The advances in HIV care over the last 30 years are remarkable. The ambitious goals of "zero new infections" and "eliminating HIV in this generation" may be possible. This process begins with diagnosing those who are not yet diagnosed, the majority of who are in underserved communities. Linking persons to care and retaining them in care remain challenging in all communities and especially among underserved. Because HIV is treatable, it can be considered a chronic disease, treatable in the context of the medical home, but that model only applies if persons remain in care. Outcomes among vulnerable populations and those who are not connected to care can only improve when creative and coordinated systems of care address the complex and intertwined problems common among underserved patients and communities. Eliminating the social and economic injustices and stigma that put patients at risk and complicate prevention and treatment remains elusive and cannot be accomplished by healthcare workers alone. This task will require ongoing creativity, advocacy, and action.

- HIV testing and treatment are key for individual health and prevention.
- HIV care is a continuum.
- HIV risk is not shared equally among all groups.
- The HIV prevention toolkit includes condoms, PEP, PrEP, treatment as prevention, and harm reduction programs.
- Combating stigma is still key to ending the epidemic.
- Successful prevention and linkage programs engage the community as an active partner.
- Team-based chronic care models are successful in reaching and retaining patients in care.
- Mental health and substance use treatment must be a priority.

Best Practices for Linkage and Engagement in HIV Care

Testing and entry into care:

- Integrate routine, opt-out testing HIV testing into primary care.
- Expand programs to increase HIV testing for high-risk people at nonclinical sites.
- Build relationships between testing sites and clinics.
  - A "warm hand-off" transitioning a newly diagnosed patient into care is ideal. Meeting a health-care provider on the day of diagnosis is particularly helpful.
- Track patients after testing and provide support to those who do not link to care after receiving an HIV diagnosis.
- Use social media to highlight HIV testing benefits and opportunities.

Patient education and support:

- Create a warm and welcoming clinic environment.
  - Greet patients by name and take time to build trust and rapport.
  - Offer bilingual services to non–English-speaking patients.
  - Use art, pictures, etc., to reflect respect for a diversity of patients and cultures.
- Provide health education addressing the basics of HIV infection, the importance of medication adherence, and retention in care.
- Use client-centered counseling styles to build capacity for self-management.
- Assess individual and structural barriers to engagement in care (i.e., fear of disclosure, lack of housing, depression, substance abuse, irregular work schedule, etc.).
  - Proactively create a care plan to address these obstacles before a patient falls out of care.
- Develop peer support and group programs for newly diagnosed patients and those at risk for falling out of care.
- Create programs to assist patients in making and keeping medical appointments.
- Use social media tools to enhance HIV education and engagement in care.
- Collaborate with local health departments and other agencies to track and reengage out-of-care patients.
- Create patient-centered community-level programs to help the highest risk individuals connect/reconnect to care.

Address structural barriers to engagement:

- Expand clinic hours to offer evening or weekend appointments.
- Create opportunities for same day or drop in appointments.
- Call, text, or e-mail patients to remind them of upcoming and missed appointments.
- Address barriers that lead to missed visits.
- Provide vouchers to cover transportation costs.
- Consider incentives such as gift or food cards for patients who keep appointments.
- Offer case management linking patients to community services.
- Assist patients in maintaining health insurance and financial stability (through employment services, safety-net programs, etc.).
- Prioritize referral to stable housing for homeless patients.
- Develop outreach services for homeless patients.
- Foster relationships with local law enforcement facilities to coordinate care transitions between prison/jail and community settings.

Co-locate services:

- Actively screen all patients for mental health issues.
- Provide on-site mental health and substance use services if possible.
- Use warm hand-offs to help patients connect to community psychiatric care or referral to alcohol or drug addiction treatment.
- Create programs to prevent treatment interruptions during detox or hospitalization.
- Screen and treat mental health and substance use disorders within the primary care setting.
- Offer on-site methadone and buprenorphine services to opiate-dependent patients.
- Use community-based DOT for antiretrovirals where appropriate to improve adherence.

Monitor and improve retention in care:

- Monitor response to HIV treatment.
- Recognize poor adherence as precursor to falling out of care.
- Assess medication adherence at every visit.
- Develop an electronic registry to follow up all active patients in the practice.
- Use registry data to develop individualized plans for reengagement.
- Regularly assess linkage and retention strategies at your clinic, trying new interventions to improve performance.
- Involve the full clinic team in linkage and retention efforts.
- Do not forget about the key roles of reception staff and medical assistants.
- Use community health outreach workers outside of clinical settings to connect with patients who have fallen out of care.
- Actively plan for and assist with the transition in care for patients who are leaving the practice due to a move or change in insurance status.

DISCUSSION QUESTIONS

1. Discuss strategies that could increase HIV testing rates among women.
2. What are some approaches that might be useful in linking to and engaging in care patients who are triply

diagnosed with HIV/AIDS, depression, and addiction to cocaine?
3. How would you counsel a 21-year-old African-American gay man who is sexually active in reducing his risk of acquiring HIV?

RESOURCES

AEGiS: AIDS Information Global Information System provides wide-ranging information on HIV/AIDS. http://www.aegis.com/.

AIDS Education and Training Center contains tips for care of HIV/AIDS patients, including comorbid conditions. http://www.aids-ed.org/.

AIDSinfo is a service of the U.S. Department of Health and Human Services. It provides information on treatment, prevention, and research. http://www.aidsinfo.nih.gov/.

AIDS.org is a site for both PWHA and practitioners who want to learn more about HIV. http://www.AIDS.org.

HIVinsite provides information on all aspects of HIV/AIDS treatment and research. www.hivinsite.org.

International AIDS Society-USA offers CME training opportunities for providers that they can utilize online or attend. www.iasusa.org.

World Health Organization: Consolidated guidelines on HIV prevention, diagnosis, treatment, and care for key populations—see www.who.int/hiv/pub/en.

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Chapter 44

Care of the Socially Complicated Patient in the Hospital

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Objectives

- Review the challenges to caring for hospitalized patients with complicated social circumstances.
- Review methods for assessing decision-making capacity.
- Offer a definition of "patients at risk" and discuss a proactive approach to provide for their safety while hospitalized.
- Provide treatment guidelines for acute alcohol withdrawal.
- Highlight best practices in interdisciplinary transitions of care.
- Discuss self-care approaches relevant to inpatient providers and staff.

INTRODUCTION

Severe illness necessitating admission to the hospital can be a time of great emotional and physical vulnerability for all patients. This vulnerability is compounded when medical illness is complicated by social circumstances such as poverty, social isolation, minority status, legal difficulties, mental disability, or chemical dependence. Evidence suggests that those living at 200% below the poverty level have a higher rate of hospitalization and receive a lower standard of care while hospitalized.[1,2]

This chapter highlights issues and challenges that arise in the care of hospitalized socially complicated patients, including initial evaluation in the emergency department (ED), ongoing care throughout the hospital course, and transition planning from the hospital.

EPIDEMIOLOGY OF HOSPITAL-BASED CARE IN THE UNITED STATES

Health-care systems and customs vary so widely across the globe that it is difficult to compare hospitalization practices and rates from one country to the next. Access to care, the number of hospital beds, the primary care infrastructure, the management of mental illness and long-term care (LTC), and the underlying health of the population all contribute to trends in hospital care.

In the United States, one of the most notable features of hospital care is its cost: hospital costs accounted for 29% of the total resources spent in 2010, the largest single share in the care system. Yet hospital utilization accounted for only 7% of the care delivered.[1] Despite no change in the age-adjusted number of hospitalizations between 1997 and 2011, inflation-adjusted hospital costs increased by 60% for all conditions.[2]

Poor patients have a hospitalization rate nearly twice that of the non-poor.[2] Among the uninsured, regardless of age, 3 of the top 10 most common reasons to be admitted in the United States involve substance abuse or mental health conditions.[1] Ironically, these higher rates of admission represent delivery of the most expensive care to those who have been deprived of more cost-effective preventive measures in the ambulatory setting.

Among the vulnerable, issues such as unstable housing, limited access to outpatient health providers, insufficient

financial resources, social isolation, and a fundamental distrust of institutional intrusion into personal life make the transition from acute hospitalization to outpatient care exceedingly challenging. These factors contribute to a longer length of stay of poor patients compared with the non-poor (5.1 days versus 3.7 days, respectively).[2]

THE SOCIALLY COMPLICATED PATIENT IN THE EMERGENCY DEPARTMENT

> Mr. Garcia is a 66-year-old man who emigrated from El Salvador. He completed approximately 6 years of school. He learned to speak and read some English while working as a waiter. The manager of his residential hotel found Mr. Garcia semiconscious on the floor of his room. The paramedics transported Mr. Garcia to the hospital to evaluate his altered mental status and labored breathing.

For many patients with limited financial and social resources, the ED is the sole option for medical care. Such patients often present for care only when they suffer from symptoms that prevent them from continuing their usual activities. Rapid collection and effective exchange of information between patient and provider is central to the delivery of quality care in the ED. Discordant language abilities between patient and provider is a tangible barrier to effective communication (see Chapter 31), yet trained interpreters are rarely used. Multiple studies demonstrate that non–English-speaking patients report less satisfaction with ED care, have a more limited understanding of their diagnosis and treatment plan, are submitted to increased numbers of diagnostic and laboratory tests, and are ultimately admitted to the hospital with higher frequency than English-speaking patients with the same chief complaint.[3,4,5]

Provider bias can contribute to treatment differences between white and non-white patients presenting to the ED with the same condition. For example, studies have found that Hispanic patients with long bone fractures received less analgesia than white patients,[6] and poor patients are often thought to be substance users even when they are not.[7] Thus, the patient–provider interaction in the ED is of signal importance.

In the ED, one of the most pressing questions is, "Does this patient's clinical condition require hospitalization in order to properly manage it?" The answer to this question requires a global assessment of the patient's social circumstances and his/her access to resources that support self-care, safe administration of medications, and the ability to seek help should the proposed treatment fail. The threshold for admission is often appropriately lowered for those with limited support and challenging social situations.

> In the ED, the triage nurse notes Mr. Garcia's temperature is 102°, heart rate 120, and an oxygen saturation of 91% on room air. The nurse finds no evidence that Mr. Garcia has been hospitalized in the past or that he is a patient in any of the hospital's primary care clinics. Despite initially insisting that he be allowed to return to his hotel, Mr. Garcia eventually agrees to be admitted to the hospital following a presumptive diagnosis of multilobar pneumonia.

THE SOCIALLY COMPLICATED HOSPITALIZED PATIENT AND THE TYRANNY OF THE URGENT

During a hospitalization, even the most engaged, activated, and empowered individuals can experience feelings of abandonment, loss of control, and vulnerability around their illness and their care. The structure and routine of the hospital day is organized for the convenience of the medical and nursing staff, and many patients, regardless of their social standing, complain about the disruptions imposed upon them—being awakened at all hours of the night, long waits for assistance, and lack of privacy. Building and maintaining trust is difficult in these circumstances, and is one of the central challenges in caring for hospitalized patients.

The inpatient setting is one where the patient is perhaps at greatest risk for what has been called the "tyranny of the urgent," where the most urgent clinical concerns subvert a provider's ability to address a patient's chronic illnesses and pressing nonmedical issues. Pursuit of diagnosis and treatment of acute clinical problems overwhelm considerations of the psychosocial conditions that may contribute to the patient's illness and recovery. The tyranny of the urgent, ubiquitous in the high-volume, high-acuity setting of a hospital, frequently undermines a thoughtful, interactive, interdisciplinary, and patient-centered approach to care.

The effects of the tyranny of the urgent can be minimized somewhat when providers concern themselves with more than just the main reason for the clinical visit or hospitalization.[8] For patients who have limited ability to advocate for themselves or are less empowered, the commitment to creating an environment in which concerns of the patient can be expressed is particularly important. Unfortunately, providers are less likely to involve minority and poor patients in patient care decisions.[9]

The inpatient setting is also fertile terrain for the growth of misunderstandings based on provider biases and assumptions, as well as discordance in belief systems between patients and the health-care team. Ethnic minorities may be wary of public hospitals because of a collective history and experience of disproportionately unjust treatment from other social institutions such as law

enforcement agencies, public schools, housing, and work opportunities. Victims of domestic violence, undocumented immigrants, and those who use illegal substances may fear the legal consequences of seeking care or being completely forthcoming about their medical histories. These fears can influence their decisions and behaviors while hospitalized. For example, what appears to the provider to be an irrational refusal of a diagnostic procedure or treatment may seem very rational to the patient who harbors unspoken concerns or fears that the cost of care may lead to financial ruin.

At the time of admission, the patient possesses most of the critical information that needs to be passed on to the provider. During the hospital course, providers accumulate information that in turn need be transmitted and explained effectively to the patient. Such crucial information sharing is often neglected, as in the case of Mr. Garcia.

> Once admitted, Mr. Garcia wants to be released from the hospital. Misinterpreting his agitation as a sign of early alcohol withdrawal, the team gives Mr. Garcia sedatives. When he pulls out his IV and begins to leave, the team requests that the psychiatry consult service declare him lacking in decision-making capacity. After talking with Mr. Garcia, the consultants determine that he does not drink alcohol. He wants to return home in order to care for his 87-year-old mother who is home alone.

As this example demonstrates, a crisis can ensue when providers do not engage in thoughtful dialogue with their patients or misinterpret social cues for biological ones. Any factor that hinders patients' ability to advocate for themselves, whether physical, emotional, or social, heightens their vulnerability when they interact with the health-care team. At the core of any potential solution is an awareness of the challenges faced by patients and the willingness and competence of the providers to address them.

In some scenarios, being truly patient-centered may require more provider-directed care. The nature and degree of a patient's involvement and ability to engage in shared decision making may vary from day to day depending on the progress and trajectory of illness. One particularly vexing situation for the inpatient practitioner is when the patient is not capable of making shared decisions. When a patient refuses or cannot truly consent to treatment, it is important for the team to elucidate and address underlying issues in order to allow the patient and team to move forward with an agreed-upon plan of care. In some cases, however, the practitioner may question the patient's decision-making capacity to accept or refuse treatment.

DETERMINING DECISION-MAKING CAPACITY

Determining decision-making capacity is a frequently encountered, complex issue in hospital care that requires a thoughtful, systematic approach by providers. All capacity assessments are made only in the context of specific decisions and clinical scenarios. Determining capacity is not a global judgment of the patient's ability to speak on his/her own behalf. Patients with mental illness, substance abuse, and mild forms of dementia retain both the ability to make autonomous decisions and the legal right to do so.[10,10a] The vast majority of capacity assessments are performed when patients refuse a provider's recommendation. Ironically, patients with questionable capacity who comply with recommendations are not generally assessed for their decision making. An incapacitated patient's consent to treatment has been termed "illusory consent."[10] This reflects providers' comfort in placing beneficence ("Let's make this intervention; I think it will help even if his cognition seems a little off") over self-determination or patient autonomy ("He is agreeing with my recommendation, but I want to be sure he has capacity to make this decision").

Assessing capacity requires that the provider make a determination about the patient's (1) awareness of his or her medical situation; (2) appreciation for the relative benefits and risks inherent in the treatment plan; (3) understanding of the consequences of forgoing treatment; (4) understanding of alternatives; and (5) ability to rationally articulate the decision and its consequences (see "Core Competency").

Decision-making capacity can be a dynamic state, waxing and waning with the condition of the patient. If the clinician questions the patient's ability to do any of these steps, he or she should review methods of increasing capacity (see Box 44-1). Patients need to have a greater comprehension of the risks and benefits when the

Box 44-1. Interventions to Improve Decision-Making Capacity

- Treat reversible medical conditions such as acute infection, hypoxia, pain, or delirium.
- Review medications as causes for sedation or confusion.
- Maximize emotional and psychiatric functioning.
  - Treat underlying mental illness or psychosis.
  - Involve family, as appropriate.
- Improve communication through:
  - Use of simple language.
  - Visual or hearing aids.
  - Trained interpreters, including sign language interpreters.
  - Low literacy materials.
  - Recurring discussions.
  - Patience.

Box 44-2. Documentation of Patient's Decision-Making Capacity[10a-10c]

- Patient's ability to communicate a consistent choice
- Patient's understanding of relevant diagnostic and treatment information
- Patient's appreciation of situation and its consequences
- Patient's rational use of the information:
  - The patient understands his or her present condition to be ……
  - The patient understands the treatment offered is ……
  - The patient feels the following will happen with acceptance of treatment ……
  - The patient feels the following will happen without treatment ……
  - The patient understands the alternatives and their consequences.
- Note any individuals who are present during this discussion, materials used, and the stability of the decision over time.

treatment is more uncertain, involves several therapeutic options, or is not necessary to sustain life.[10c] It is advisable for the provider to document this discussion in the chart and communicate this to the patient's other providers (see Box 44-2).

The evaluation of capacity can yield one of two outcomes for the patient refusing treatment. The provider may conclude the patient has capacity. In this case, if the patient continues to refuse treatment, then the provider is obligated to respect the patient's autonomy and not pursue the proposed intervention.

MEDICAL PROBATE

If the patient is deemed to lack decision-making capacity about a treatment that clinicians feel is beneficial but not emergently required, and there are no advance directives or surrogate decision makers who can consent on the patient's behalf, then it is appropriate to seek court adjudication formalizing that plan to proceed with care against the patient's wishes.

In some parts of the United States, providers may apply to the public guardianship courts to grant a petition for medical probate. If granted by the court, medical probate authorizes the medical team to serve as a surrogate decision maker for the patient for issues relevant to the medical care of the patient. If the patient demonstrates capacity for other medical decisions, then the medical probate does not override his or her autonomy in that realm. Medical probate does not allow providers to use psychoactive medicines to treat an underlying psychiatric illness against the patient's will. Such powers require an alternative formal petition and hearing by the courts. And medical probate does not allow providers to make decisions about housing or placement in rehabilitation facilities against the patient's will. These decisions require court authority provided through the conservatorship process.

For questions or concerns around appropriateness of legal holds or conservator processes, we always recommend to always involve your institution's risk management department or equivalent legal counsel.

CAPACITY VERSUS COMPETENCE

Although often used synonymously, medical decision-making "capacity" and "competence" are distinctly different entities. Capacity is the ability of a person to understand and make medical decisions based upon that understanding. Providers make this determination through the approach discussed earlier. Competence, on the other hand, is a legal determination, and refers to the ability not only to comprehend but also to act upon that comprehension. Competence encompasses the ability to successfully manage physical, emotional, and financial health. Competence requires a person to have "sufficient ability or skill" and the legal authority to exercise it.[11] Decision-making, cognition, psychiatric stability, and functional abilities all contribute to competence. The courts, usually through the public guardian's office, oversee determination of competence. The competency assessment will inform the patient's access to financial tools, such as pensions or general assistance, while also informing placement options.[12] A patient may be deemed incompetent to manage his or her financial affairs, yet retain sufficient decision-making capacity to consent to medical treatment, such as a colonoscopy.

After further discussion with Mr. Garcia, the team determines that he has capacity to make the decision to leave the hospital as he desires. His elevated white blood cell count since admission is trending down and he no longer requires supplemental oxygen. He is, however, still experiencing low-grade fevers, and the team recommends that he stay in the hospital until he is afebrile. Despite the team's recommendations, Mr. Garcia leaves the hospital with oral antibiotics, strict return precautions, and a post-hospitalization appointment in the general medicine clinic. On leaving, Mr. Garcia is asked to sign an against-medical-advice form.

SELF-DISCHARGES

The majority of hospital discharges occur under safe circumstances, with the patient and treating providers in agreement that necessary inpatient evaluation and

treatment is complete. Up to 2% of hospital discharges, however, may be considered against medical advice (AMA) or absent without leave (AWOL) discharges.[13] The hospital-based provider should be aware of the definitions, risks, and appropriate steps surrounding these often challenging situations.

AGAINST MEDICAL ADVICE

AMA discharge occurs when an adult patient with medical decision-making capacity voluntarily decides to leave the hospital before the treating provider recommends discharge.[13] This requires a discussion between the patient and the provider about the benefits of continuing hospitalization, potential risks of premature leaving, and alternative discharge options. Patient predictors of AMA discharge include lower socioeconomic class, male sex, younger age, publicly subsidized or no insurance, substance abuse, prior history of AMA, and lack of a primary care physician.[14,15] AMA discharge has been associated with increased readmissions,[16] morbidity, and mortality.[17] Physicians faced with this type of discharge may struggle with a desire to respect principles of patient autonomy while continuing to act in a manner they feel is best for the patient's health. Many hospitals ask or require patients leaving AMA to sign specialized discharge forms, though there exists no clear legal basis for this formality.[18] The creation of a potentially adversarial relationship at the time of discharge has the potential to erode patient trust and willingness to return for care. It is important in these situations not to sacrifice the therapeutic alliance. Providers should continue to plan, as best able, for a safe and successful discharge including discussion of alternative (though potentially suboptimal) treatment options, coordination with social services, scheduling outpatient follow-up, and filling needed prescriptions.

ABSENT WITHOUT LEAVE

An AWOL discharge occurs when an adult patient with medical decision-making capacity leaves the nursing unit or hospital before planned discharge and cannot be located. The term derives from military language describing leave of a post without permission. When pertaining to the hospital, this is a type of AMA discharge; the patient has gone missing before appropriate discussions have taken place, but he or she is not felt to be immediately at risk. Similar efforts to ensure a safe discharge plan should be made, including attempts to contact the patient, his or her emergency contacts, and the primary care provider (PCP). Documentation should be made in the medical record of the patient's condition when last seen as well as a list of current medical problems and medications. Such documentation not only serves a legal purpose but also can help coordinate care should the patient re-present to the hospital, another institution, or an outpatient provider.

AWOL AT RISK PATIENT

> Mrs. Schwartz is a 57-year-old female who lives alone. She is brought to the hospital because of increasing confusion over the past 2 weeks. On admission, she is pleasant and directable but clearly confused as to the date, place, and reason why she was brought to the hospital. Her initial workup reveals a community-acquired pneumonia and she is admitted for antibiotics and further workup of her impaired cognition. On hospital day 2, Mrs. Schwartz is noted to be missing from the inpatient nursing unit. It is later discovered that she had wandered away from the hospital and into the middle of a busy street, where she was struck by a car and suffered a pelvic fracture.

Patients who exhibit a compromised mental status can be at great danger if they prematurely leave the hospital without appropriate planning and supervision. Examples of such patients include those with chronically impaired cognition or acutely altered sensorium, as well as those on a surrogate or legal hold. Even if these patients comply with the plan of treatment while in the hospital, they may not be able to keep themselves physically safe outside the hospital (as in the aforementioned example) or to meet basic self-care needs of providing food, clothing, and shelter. We recommend early, proactive identification of this special class of vulnerable patients and the use of specific terminology when discussing these patients, such as "patient at risk." The medical provider should determine whether a patient is "at risk" and, if so, communicate this determination to the unit staff in order to activate relevant monitoring protocols. The medical team does not control all possible risks of injury to a "patient at risk" in the hospital. The hospital as an organization has responsibility to provide the necessary resources to keep the patient safe from harm during the inpatient stay and to maintain a safe environment for the patients it serves. A hospital can be found legally liable when it fails to ensure the patient's safety and well-being during the inpatient stay.[19]

Determining "at-risk" status, as well as decision-making capacity, should be a part of the initial and ongoing assessment of the patient during hospitalization.[20] A simple test is to ask yourself, "Would I be worried about this patient's safety if I heard that he/she had left AWOL?" Communication across interdisciplinary teams is a vital component of keeping the "patient at risk" safe while in the hospital.

Individual institutions often have specific policies regarding the care and monitoring of "at-risk" patients,

which may involve the use of a bedside sitter or "coach," room placement in close proximity to nursing stations, bed alarms, wander management alarms, or, as a last resort, physical restraints. The medical and nursing plans of care should reflect what and how information is communicated to the patient. Patients who are "at risk" have the right to as much information about their medical care as patients with normal cognition. Information should be presented in the simplest language, free of medical jargon, using the patient's own words, if possible. Reducing dependence on memory by providing small amounts of information at a time and the use of visual aids such as photographs and drawings have been shown helpful in optimizing communication between providers and patients who lack capacity.[21]

Despite the best institutional and provider efforts, a "patient at risk" may leave the nursing unit unwitnessed prior to her or his scheduled discharge. These patients are at particular risk of injury. Institutions should have protocols for patients both with and without decision-making capacity who leave AWOL. We recommend using a special designation for such patients, such as "AWOL at risk," when alerting staff and security personnel about the missing individual. Providing a precise designation can then trigger a specific plan of action. Box 44-3 details the systematic response that San Francisco General Hospital developed for "AWOL at-risk" situations.

ALCOHOL WITHDRAWAL

> Ms. Johnson is admitted from clinic for a diabetic foot infection. She undergoes amputation of her right first toe and is treated postoperatively with intravenous antibiotics. On hospital day 2, Ms. Johnson's nurse notifies the orthopedics team that the patient is tremulous, diaphoretic, and confused. On further questioning, Ms. Johnson states that she usually drinks two bottles of wine daily, with her last drink the night prior to admission.

Patients leave the hospital AMA or AWOL for a variety of reasons, not the least of which are social-related concerns such as caring for dependent family members or children, concern for the well-being of pets, as well as financial and housing concerns such as retrieving pay checks or ensuring the timely paying of one's rent. However, many patients leave prior to completion of treatment because of undertreated pain or anxiety and unrecognized substance or alcohol withdrawal. In Ms. Johnson's case, the care team suspects the patient may be suffering from alcohol withdrawal.

The alcohol withdrawal syndrome manifests as a cluster of symptoms that may occur in alcohol-dependent patients after cessation or reduction of substantial and prolonged alcohol use. The hallmark of alcohol withdrawal is a heightened autonomic arousal characterized by tachycardia; hypertension; diaphoresis; tremor; visual, auditory, or tactile hallucinations; agitation; and seizure. Withdrawal manifestation may be protean and providers should maintain a high level of suspicion for alcohol

Box 44-3. Organization Response for Missing "AWOL at-Risk" Patient

- The primary nurse will notify the patient's principal hospital provider.
- The primary nurse will notify the charge nurse or nurse manager who will notify the nursing administrator on duty of an "AWOL at-risk" patient.
- Utilizing situation/background/assessment/recommendation, the primary nurse will notify the institutional safety officers to provide a full description of the patient and initiate a search to include hospital buildings, stairwells, tunnels, outside grounds, and surrounding public areas.
- Clinical staff from the patient's nursing unit, who can rapidly recognize the patient, will conduct a search of common areas.
- To mobilize an organization-wide response, the institutional safety police will alert all staff to the existence of an AWOL at-risk scenario by announcing "Code Green" through overhead speakers. This overhead announcement alerts staff to call a designated number for a complete description of the patient. Hospital operators send this same descriptive information to all staff pagers.
- All departments will conduct a search for the missing patient within their areas and report the results to a predetermined centralized location if the patient was not found.
- The patient's primary hospital providers will contact the patient's home, family members, or emergency contact to advise them of the situation and obtain relevant information. The providers will document this contact or attempt at contact in the medical record and describe the approximate time the patient was found missing, a brief description of the patient's condition, a list of the patient's current medications, and efforts made to locate the patient.
- If the patient has been seen or found, this information is communicated directly to the institutional police department.
- If found, safety officers or clinical staff will bring patient back to the unit for evaluation by the primary service.
- If not found, safety officers will notify the local police department to initiate a missing persons report.

withdrawal in admitted patients demonstrating one or more of these symptoms.

Benzodiazepines have been shown to be one of the most effective classes of drugs in the management of alcohol withdrawal, with stronger evidence of efficacy than anticonvulsants, muscle relaxants, or antipsychotics.[22] For inpatient management of alcohol withdrawal, the revised Clinical Institute Withdrawal Assessment for Alcohol (CIWA) scale, a validated 10-item assessment tool, can be used to quantify and follow up the severity of alcohol withdrawal while guiding appropriate medication administration.[23]

Benzodiazepines (frequently lorazepam, diazepam, or chlordiazepoxide) can be administered based on CIWA scores, allowing for an automated and protocol-based approach to sedative dispensing.[24] The choice of a particular agent frequently varies based on hospital formulary and provider experience. For patients at high risk of alcohol withdrawal (e.g., those with a history of withdrawal-related seizures or delirium tremens), providers may consider initiating a standing benzodiazepine taper on admission. CIWA assessment and symptom-triggered benzodiazepine dosing can then be used for breakthrough symptoms (see "Resources").

Hospitalization offers a unique opportunity to identify and counsel alcohol-dependent patients. Along with providing social work and case management services, the benefits of cessation and treatment options for those ready to change should be discussed. In addition to referrals to substance abuse counseling programs, patients may be interested in adjunctive pharmacologic therapy. Naltrexone, an opioid antagonist, has been shown to decrease the quantity and frequency of alcohol consumption in patients with alcohol dependence.[25] For motivated patients, in the absence of contraindications such as liver disease or concomitant opioid use, initiation of naltrexone therapy may occur at the time of discharge with follow-up care in place for ongoing counseling and prescription.

TRANSITIONS OF CARE: DISCHARGE PREPARATION

Transitions of care, such as hospital admission and discharge, are complex processes involving multiple caregivers and handoffs. Such transitions therefore require good systems in place in order to happen safely and smoothly. For medically underserved patients and for under-resourced care systems, it can be especially challenging to ensure optimal transitions of care. Best practices in care transitions include medication reconciliation, comprehensive discharge planning, patient/caregiver education, high-quality communication between providers, and prompt follow-up with an outpatient provider after discharge.[26]

Ms. Nguyen, a 72-year-old woman with chronic heart failure, is admitted to the hospital for a heart failure exacerbation. On admission, her medical team confirms her outpatient medication regimen and adjusts the regimen for in-hospital care, and assesses her functional status at home. She gets daily updates regarding her condition and her progress toward her discharge goal. The team works with her and her primary caregiver (her daughter) to prepare a post-hospital plan that she can understand. Nurses provide education about self-management of heart failure. Ms. Nguyen is discharged with a copy of her new medication regimen, language-concordant discharge instructions, and a follow-up appointment with her primary care provider (who receives a copy of her discharge summary). After discharge, a home health nurse visits her to do further self-management teaching and provide her with a scale so she can weigh herself daily. A nurse case manager at Ms. Nguyen's clinic also calls her regularly to check on her weights and recommend medication adjustments in case of weight gain.

MEDICATION RECONCILIATION

Both hospital admission and discharge are high-risk periods for medication errors.[27] On admission, it is important to ascertain what the patient is actually taking at home (which may differ from what has been prescribed). Upon discharge, the care team should review the admission list of outpatient medications, reconcile it with the inpatient medication list, and create an updated list of discharge medications, ensuring a rationale for any changes. Structured medication reconciliation reduces medication discrepancies and adverse drug events, and reduces readmissions as part of a comprehensive intervention.[28]

DISCHARGE PLANNING

Creating an individualized discharge plan helps the patient and family in the transition out of the hospital, as well as reducing hospital lengths of stay and readmission rates.[29] Discharge planning addresses several important domains: the patient's anticipated level of function post-discharge; the most appropriate setting for post-hospital care; and medications, equipment, and other resources needed to support the patient in the community or another facility. Many patients need either additional resources to support them in the community or a brief stay in a subacute facility before returning to the community. Post–acute care (PAC) resources are generally shorter term and focused on recuperation and rehabilitation; LTC resources are used for patients with less chance of recovery to their pre-hospitalization level of function. Table 44-1 lists common postdischarge resources of both categories.

Table 44-1. Examples of Postdischarge Facilities and Programs[29a]

Resource	Post–acute care vs. long-term care	Description
Inpatient rehabilitation facilities	PAC	Provide intensive rehabilitation; at least 3 hours of PT/OT per day
Skilled nursing facility	PAC	Provide less intensive rehabilitation; wound care; complex medication schedules
Long-term care hospital	PAC	Complex care such as ventilator care
Home health care	PAC	Home visits by registered nurses and/or PT/OT
Outpatient rehabilitation	PAC	Facility-based PT/OT
Hospice/palliative care	PAC	Home- or facility-based supportive care for patients with terminal illnesses; focus is on symptom relief and comfort
Medical respite[29b]	PAC	For homeless patients well enough to be discharged but too sick to be on the streets or in shelters Provide wound care; medication regimen management; transportation to appointments
Shelters, including specialized women's shelters	PAC	For homeless patients; women's shelters used for victims of intimate partner violence; staff can help bridge to housing
Home care/personal care	LTC	Supportive in-home care for ADLs/IADLs by non-skilled providers
Assisted living	LTC	Residential centers for adults with some self-care capabilities
Nursing home	LTC	Long-term care for patients dependent on ADLs/IADLs
Day care or adult day health center	LTC	Care provided in facility during part of the day; nonresidential; some provide medical services
Board and care	LTC	Room and meals provided; no skilled care
Single room occupancy (SRO) hotel	LTC	Room only; some programs fund rooms for homeless patients

Abbreviations: ADLs, activities of daily living; IADLs, instrumental activities of daily living; LCT, long-term care; OT, occupational therapy; PAC, post-acute care; PT, physical therapy.

COMMUNICATION

High-quality communication, both with the patient and family and with the patient's PCP, is essential. Patient education using the "teach-back" method, where patients restate instructions or concepts in their own words, is a key intervention in many of the evidence-based care transition programs.[26] Patients should be educated about major diagnoses, medication changes, self-care, and warning signs and what to do if problems arise. Discharge summaries should be sent to the patient's PCP shortly after discharge and should include a summary of the hospital course, medication changes, pending tests, and needed follow-up. Specific interventions have been shown to improve both the timeliness and quality of discharge summaries.[30]

READMISSIONS: PREVENTION

Hospital readmissions are unfortunately common, often for the same condition. The 30-day readmission rate approaches 20%.[31] Although no individual intervention has been shown to reliably decrease the rate of hospital readmission,[32] there are several comprehensive discharge-focused programs, which have demonstrated significant reductions in both readmissions and cost (Table 44-2 and "Resources").

These programs have been most successful in populations of elderly patients and have not been as well studied in younger indigent adults. A clustered randomized controlled trial of low-income hospitalized adults, which used similar interventions as the aforementioned programs, showed an improvement in the quality of care transitions but did not reduce readmissions.[33]

READMISSIONS: PREDICTING

There have been many efforts to develop tools to predict a hospitalized patient's risk for readmission after discharge. A systematic review of risk prediction models in 2011 found that most models had poor predictive ability; it was difficult to capture social information from the electronic health record (EHR); and hospital and system-level factors were not captured.[34] Additionally, the prospective use of risk prediction models has not been shown to reduce readmissions.[35]

CHRONIC DISEASE MANAGEMENT

Many chronic medical conditions predispose patients to hospitalization. There are several evidence-based programs focused on the patients in the community, with the goal of improved disease management and decreased

Table 44-2. Evidence-Based Programs to Reduce Hospital Readmissions

Program [Lead Author/Organization]	Summary of Program	Outcomes
Care Transitions Intervention (CTI)	**Who:** Transition coach (advanced practice nurse) **What:** Helps patient create personal health record, educates patient, does home visit and three follow-up phone calls after discharge Goal is to empower patients in self-management	Quasi-experimental cohort in 2014 (geriatric patients): decrease in cost utilization[35a] RCTs (geriatric patients): decrease in readmissions (2009 and 2006) and cost (2006)[35b,35c]
Project Better Outcomes for Older Adults through Safe Transitions (BOOST)	**Who:** Varies by site of implementation **What:** Four components: • Comprehensive risk assessment on admission – Tool: 8P screening tool: screens for 8 high-risk conditions and suggests specific interventions[35e] • Patient-centered discharge process, including education with teach-back and a f/u appointment scheduled before discharge • Standardized PCP communication • 72-hour follow-up call for high-risk patients	Semicontrolled pre-post study in 2013: decrease in readmissions[35d]
Project Re-engineered Discharge (RED)	**Who:** Nurse discharge advocate **What**: Coordinates discharge plan, creates after-care hospital plan and faxes plan to PCP, educates **Who:** Pharmacist **What:** Makes follow-up phone call after discharge (Currently implementing a virtual [electronic] discharge advocate in their program)	RCT in 2009 (adult patients): decrease in readmissions and ED visits[35f]
Transitional Care Model (TCM)	**Who:** Nurse specialist **What**: Creates discharge plan, educates patient, and does phone follow-up after discharge	RCTs in 2004 (patients with CHF), 1999 and 1994 (geriatric patients): decrease in readmissions and cost[35g-35i]

Abbreviations: CHF, congestive heart failure; ED, emergency department; PCP, primary care provider; RTC, randomized controlled trial.

hospitalization, as well as programs based on the ED (Table 44-3 and "Resources").

SELF-CARE FOR HOSPITAL PROVIDERS

For providers in most clinical environments, caring for hospitalized patients is stressful, and caring for socially vulnerable patients in under-resourced settings compounds that stress. While self-care is addressed at length elsewhere (see Chapter 45), hospital-based providers face unique challenges, and there are some specific resources that can help them mitigate their stress.

The high-acuity nature of hospital care means that medical errors can quickly lead to devastating adverse outcomes. Medical errors are unfortunately common and lead to thousands of preventable deaths each year.[36] In addition to causing suffering for the patients and families, medical errors can cause trauma to the health-care providers involved; the provider is described as the "second victim" of the incident.[37] The majority of physicians have experienced serious adverse patient events within the past year, and physicians experience high levels of distress, depression, and burnout.[38] To discuss the need to address provider distress, the University of Missouri Health Care System set up a Second Victim Rapid Response Team with a three-tiered model of support after high-risk clinical events.[37] Tier 1 provides local support from peers who have received basic training; tier 2 provides additional support from trained peer supporters; and tier 3 provides professional counseling. Brigham and Women's Hospital implemented a physician-to-physician peer support program after finding that physicians were not utilizing the group support already in place.[38]

Schwartz Center Rounds (SCR) is a program that was initially developed at Massachusetts General Hospital in 1997, and it is now offered at more than 350 health-care facilities around the United States and other countries.[39] The purpose of SCR is to "offer a regularly scheduled time during our fast-paced work lives to openly and honestly discuss social and emotional issues that arise in caring for patients."[40] The format is a confidential, multidisciplinary discussion about actual patient cases at the institution. A facilitator leads

Table 44-3. Outpatient Programs for Disease Management and High Utilizers

Program [Lead Author/Organization]	Summary of Program	Outcomes
Care Management for High Cost Beneficiaries (CMCHCB) [Massachusetts General Hospital (MGH)] Other high-utilizer programs are well summarized[44]	– Nurse case managers develop individual relationships with high-cost patients; conduct comprehensive assessment; develop care plan with PCP and team – Care plan is coordinated across services (ED visits, admissions) – Electronic dashboard used – Comprehensive team includes pharmacist, medical director, project manager, financial counselor, community resource specialist	2013 evaluation of MGH program (RCT): increased satisfaction and physical functioning; reduced ED visits and acute hospitalizations, but not readmissions; reduced mortality; substantially decreased costs[45]
Chronic Care Model (CCM)[45a]	– Ambulatory care-based model focusing on longer-term management of chronic conditions – Focuses on all patients with chronic disease, not just high users – Six components: self-management support, decision support, delivery system design, clinical information systems, health-care organization, and community resources	2009 literature review of trials using CCM from 2000–2008: improvement in both processes and clinical outcomes, cost outcomes unclear[46]
ED case management for frequent users of ED services	– SW case managers work with ED high utilizers to help with social issues, housing, substance abuse, etc.	RTC in 2008: patients had fewer ED visits and a lower burden of psychosocial problems but did not decrease use of other services; lower ED costs but not lower costs overall[47]

Abbreviations: ED, emergency department; PCP, primary care provider; RTC, randomized controlled trial; SW, social worker.

discussion and summarizes salient points. Caregivers at sites offering SCR have been found decreased perceived stress and improved ability to cope with psychosocial demands of care.[41] The SCR has been successfully implemented internationally with similar benefits to caregivers.[42]

Teaching hospitals can leverage their education time to include a focus on the psychosocial aspect of patient care in addition to medically focused teaching. Relationship-Centered Rounds (RCR), an hour-long discussion on the Department of Family and Community Medicine's inpatient teaching service at San Francisco General Hospital, have occurred weekly for over 30 years (G. W. Saba, personal communication, 2014).[43] A behavioral psychologist facilitates RCR, with the topics and main discussion generated by the learners. RCR provide a focused, intentional, and predictable forum for reflection on the relationship-centered care of hospitalized adults and those involved in their care (family, community, PCP, inpatient team, consult services, and other providers). The learners' well-being and development as healers are central to the discussions.

CONCLUSION

Admission to the hospital frames a time of significance and stress for socially complicated patients. Patients do not "check" their social challenges at the hospital door. Focusing exclusively on the diagnosis and treatment of acute clinical illness may obscure the contribution of psychosocial conditions to a patient's illness and hinder his or her recovery. Providers must understand the interplay between a patient's acute or chronic conditions and his or her social circumstances, such as poverty, social isolation, minority status, chemical dependency, and mental disability. All staff, knowing that vulnerable patients are at risk of receiving less compassionate and patient-centered care than well-resourced patients, should make an effort to reduce disparities in their own institutions. Providers must be able to assess decision-making capacity in patients with impaired cognition or when the patients disagree with a proposed plan of care. Being familiar with common conditions affecting socially complicated patients in the hospital, such as alcohol withdrawal, can optimize the care provided. It is especially important to develop robust discharge plans for vulnerable patients in order to ensure optimal transitions of care. If managed skillfully and compassionately, hospitalization may become an opening for a patient-centered approach to the longer-term issues that socially complicated patients face. The provider can then experience the gratification of partnership with a patient on the mend while contributing to a collaborative, respectful healing environment in the hospital.

- Consider how the patient's social circumstances may challenge his or her ability to optimally manage his or her health.
  - Use professional interpreters.
  - Engage appropriate social services when the provider has determined that lack of social resources such as reliable access to food, shelter, or housing is undermining the medical treatment plan.
- Understand how outside social pressures may be contributing to the anxiety or agitation of your hospitalized patient.
- Always consider the possibility of drug and alcohol withdrawal in the hospitalized patient.
- Have a stepwise approach to determining capacity and optimizing decision-making ability in the hospitalized patient.
- Interdisciplinary engagement with nursing, case management, and social services is vital to address the multiple needs of the socially complicated patient.
- Ensure safe discharge planning continues to occur during AMA or AWOL discharges.

At the time of admission:

- Neglecting appropriate communication with the patient, including the use of interpreters at any point in the hospitalization.
- Discharging patients from the ED without considering the psychosocial challenges that impede their ability to care for themselves.

During the hospital course:

- Underestimating how confusing and frightening the hospital environment can be to patients.
- Underestimating the degree to which marginalized patients experience the hospital as another untrustworthy social institution.
- When addressing the patient who disagrees with the treatment plan, assuming he or she lacks capacity, rather than exploring his or her unspoken concerns.
- Allowing the acuity of other patients to distract one's full attention from the development of a successful discharge plan for the stabilized patient ready to leave the hospital.

At the time of discharge from the hospital:

- Failing to consider the importance of stable housing and social support in improving the patient's health.
- Failing to assess the patient's ability to adhere to the discharge plan, including access, understanding, and functional capacity to take medications or change dressings.
- Incompletely appreciating and assessing the patient's level of understanding about how to take his or her medications.
- Neglecting to plan for as safe and thorough a discharge as possible when a patient leaves the hospital AMA.

DISCUSSION QUESTIONS

1. Consider from your own experience how an acute illness and the recovery from that illness affected the life and family of a loved one or friend. How might financial limitations have affected the outcome?
2. You are admitting a patient from the emergency department who does not speak English and your hospital does not have a suitable interpreter to facilitate the interaction. What strategies might you pursue to get further information?
3. Consider any patient admitted to the hospital. What vulnerabilities might he or she experience? How are these vulnerabilities, common to many patients, compounded among patients who do not speak English well or patients with an underlying mental illness?
4. What strategies can providers employ to reasonably ensure that the medical care and treatment offered is concordant with the patient's needs, desires, and values?
5. What preparations or follow-up plans should providers make for a patient who leaves AMA or AWOL from the hospital? When a patient leaves despite your recommendations, should he or she receive the same standard of discharge planning?
6. Reflect on your experiences with patients who lack decision-making capacity in the hospital. Are patients who cooperate with our recommended plans of care less likely to have their decision-making capacity evaluated?
7. Which aspects of care transitions are more challenging for homeless patients? What interventions could assist such patients as they are discharged from the hospital?

RESOURCES

CIWA Symptom Triggered Scale example: http://www.aafp.org/afp/2004/0315/afp20040315p1443-f1.gif.

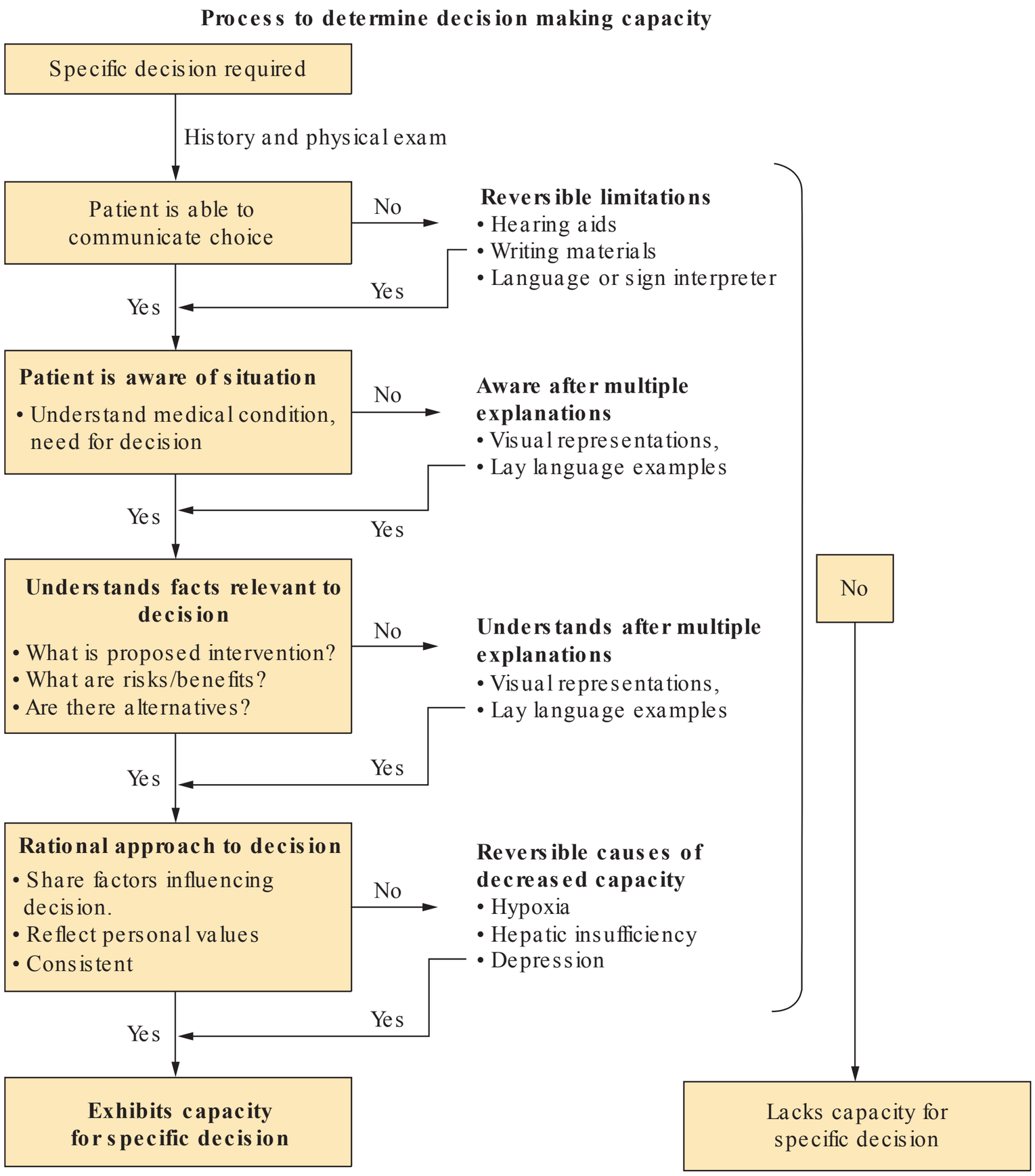
Transitional Care Model (TCM): http://www.transitionalcare.info/.

Care Transitions Intervention (TCI): http://www.caretransitions.org.

Project BOOST: http://www.hospitalmedicine.org/boost/.

Project Re-Engineered Discharge (RED): http://www.bu.edu/fammed/projectred/index.html.

Chronic Care Model: http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2.



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Chapter 45

Caring for Ourselves While Caring for Others

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Objectives

- Distinguish between engaged and dissociated health-care work.
- Define burnout, compassion fatigue, and compassion satisfaction.
- Recognize risk factors for burnout and compassion fatigue and protective factors for compassion satisfaction.
- Identify strategies for preventing burnout and compassion fatigue and for promoting compassion satisfaction

Andrew is a primary care clinician who has been working in a community health center for 9 years. This year, his ill parents have moved into the home he shares with his partner and children. At first, coming to work felt like a reprieve from the stress at home, but now he is finding himself resenting his patients, particularly those with intensive needs. He feels angry with patients who do not adhere to the recommended treatment plan, irritated by patients who present with undifferentiated and persistent complaints, and frustrated with the systemic barriers he faces to providing quality patient care. He sees little point in investing energy into helping people who do not seem to improve.

INTRODUCTION

Caring for underserved populations is an inevitably challenging endeavor. While health-care providers throughout medicine struggle with issues of burnout and compassion fatigue, providers of underserved populations are confronted with a greater burden than most. The difficulties unique to this work are numerous: the work environment is often unfavorable, institutional barriers to providing quality care seem insurmountable, financial limitations are frequent, and colleagues can appear "burned out" or unhelpful. Worse, providers regularly find themselves witnessing the injustices, traumas, and tragedies suffered by their patients. A provider who remains sensitive to the human struggles of his or her patients will experience a steady stream of complex emotions that require attention. Self-care becomes essential.

A common misunderstanding of the notion of self-care is that self-care requires engaging less with work or distancing oneself from one's patients. While adequate rest and time away from work are important, distancing, or "depersonalization," is in fact one of the features of burnout and rarely leads to a happier, more satisfied health-care provider.[1] In trying to protect themselves from the pain associated with their difficult work, many providers unintentionally depersonalize their work to the extent that they no longer take pleasure in it or engage wholly in it. Besides being miserable for the provider, this shift has been shown to lead to increased errors and worse patient outcomes.[2] Particularly in a population that is already subject to marginalization, a provider who is disengaged and uninterested can be genuinely harmful.

The task, then, is to find a way to engage deeply in one's work, to confront the struggles associated with it, and to continue to feel empathy for patients, all while remaining healthy and satisfied as a provider. In this chapter, we explore the features of burnout and what is known about its causes and cures. We will also explore a newer concept, compassion satisfaction, and discuss its impact on the provider and patient experience.

BURNOUT

DEFINITION

Herbert Freudenberger[3] first mentioned the term "burnout" in 1974. In his original conception, burnout was the last in a series of 12 stages that began with the "compulsion to prove oneself" and ended with "inner emptiness," followed by "depression" and then "burnout syndrome." In this conceptualization, burnout syndrome was described as a physical and emotional collapse, often involving suicidal ideation.[3]

Our understanding of burnout has evolved from this somewhat dramatic description, and we now understand it to encompass a spectrum of experiences, from mild burnout to severe burnout. Burnout is understood as a composite of three related psychological states: depersonalization/cynicism, emotional exhaustion, and a sense of inefficacy or helplessness. The Maslach Burnout Inventory is designed to measure these features and can allow employers or employees to monitor the effectiveness of interventions designed to limit or prevent burnout.[1]

The term "burnout" implies that something that was once present has been burned away, and that the sufferer of burnout has lost his or her capacity for engagement, efficacy, and energy. This is not the case. Burnout is extraordinarily common among health-care providers, with estimates of prevalence ranging from 25% to 70% depending on the population studied.[4] The majority of providers will experience burnout at some point in their careers, often multiple times, and most will recover. Burnout, for most providers, is a temporary state. For this reason, some researchers suggest that we find a different, more descriptive term that does not imply such a drastic, unsalvageable situation.

Compassion fatigue is one example of an alternative formulation that acknowledges its normal and temporary nature. Compassion fatigue is described as the gradual lessening of compassion over time. It is understood that repeated exposure to suffering will naturally lead to periods of compassion fatigue, but that this state is recoverable.

A third term, secondary traumatic stress, describes a similar experience in which providers are repeatedly stressed by their exposure to patient traumas. These repeated micro-traumas lead to a state of depersonalization and fatigue that is considered unfortunate but normal and temporary.

IMPACT ON PROVIDER

The impact of burnout, compassion fatigue, and secondary traumatic stress on the health care provider is obvious. Studies confirm increased rates of depression, anxiety, and suicidality among providers with high burnout scores on the Maslach Burnout Inventory.[5] Nurses and physicians with burnout are more likely to consider leaving their jobs, and burnout contributes to increased turnover, sick days, and attrition from medicine.[6] In addition, there is evidence of increased inflammatory markers and increased rates of cardiovascular disease among those who suffer burnout.[7]

The consequences of burnout spread beyond the provider. Studies show a significant increase in medical and surgical errors, higher postoperative recovery times for patients with burned out surgeons, increased rates of wound infection among patients with burned out nurses, increased self-report of suboptimal care by burned out providers, and consistently worse patient satisfaction when providers are experiencing burnout.[8] From the perspective of a manager or system leader, there is no question that burnout leads to increased waste and worse patient outcomes.

RISK FACTORS AND PROTECTIVE FACTORS

An awareness of one's own modifiable and unmodifiable risk factors for burnout can help a health-care provider manage these risks more actively. Known risk factors for burnout can be divided into work-related factors, demographic factors, life stress–related factors, and psychological or temperamental factors (see Table 45-1).

Workplace Factors

Both employers and employees can improve working conditions and prevent burnout by attending to a number of specific features that have been shown to correlate with burnout among health-care workers.

Control

Primary among work-related predictors of burnout is a sense of control at work.[9] Health-care providers who work in underserved settings are particularly vulnerable to a sense of being overwhelmed, inefficient, or, worse yet, ineffective. They often have little control over the services and treatments that are available to their patients and, more importantly, over the social determinants of health that have an impact on their patients' lives. Finding ways to maintain a sense of control at work is a powerful

Table 45-1. Protective Factors and Risk Factors for Burnout

Protective Factors for Burnout and Promoters of Compassion Satisfaction	Risk Factors for Burnout
Work environment	
Sense of control, as promoted by fair policies and responsive leadership	Lack of control
Regular re-engagement with a shared mission and meaning	High burden of meaningless tasks, lack of organizational alignment
Electronic medical records that make systems of care more efficient	Electronic medical records that do not facilitate patient–provider interaction
Reimbursement systems that promote every team member working at the top of their license	Reimbursement systems that do not promote team-based care, such as fee for service models
Ability to work part time if desired	Inflexible schedules
Fair compensation	Inadequate compensation
Teamwork with stable teams over time	Provider is responsible for all aspects of care
A supportive work culture in which providers feel safe discussing difficult issues	A culture that shames people for mistakes or otherwise makes it difficult to discuss problems
Teaching and leadership roles	
Personal factors	
Emotional attunement, empathy, compassion, gratitude, and perspective taking	Alexithymia, avoidant, passive aggressive, dependent, or anti-social personality characteristics
Personal reflection on core values and role of work in expressing these values	Disengagement or dissociation from work
Self-care and stress management practices, including meditation, religious and spiritual engagement, exercise, hobbies, and psychological practices that promote helpful mental habits	Life stressors outside of work
Social support outside of work	Isolation or withdrawal
Relationships with coworkers and patients	Isolation in the workplace, depersonalization of patients
Special training in trauma care	High exposure to trauma, either personal or work related
Breaks: micro-breaks, weekends, and vacations	

and important strategy for preventing burnout. A sense of increased control can derive from placing health-care workers in leadership positions, encouraging their participation in projects with a clearly defined purpose and concrete results, and allocating time for creative or administrative endeavors beyond the daily work of patient care. Management styles that allow employees a voice and the opportunity to make change in the workplace can support employees in cultivating a sense of control. Regular meetings in which employees have the opportunity to contribute to management decisions or retreats that allow for creative group thinking about work-related issues are another way to build a culture of self-efficacy.

Shared Mission and Meaning

The health of an organization is dependent upon coherent alignment with a shared mission.[10] Providers who work with underserved populations are more likely to continue if they feel their work aligns with their personal mission.[11] Provider satisfaction is best in settings where organizational values and mission are clearly stated, frequently discussed, and evident in the work at all levels.[12] The simple but critical experience of being surrounded by colleagues who share values and commitment to a joint mission can be extraordinarily supportive and nourishing.

Systems of Care

Care-related administrative tasks might add hours of uncompensated time and suffocates contentment with meaningful work. Research on this phenomenon is minimal, but many health-care providers complain that increasing emphasis on business tactics and checkbox-driven care undermine a sense of meaning or mission, and can deflate a provider's sense of competence and efficacy.

Providers note increasing frustration with electronic medical records that dictate the priorities of care and interfere with meaningful interaction with patients. Because the current generation of electronic medical records are not generally optimized for use by providers and patients but are instead optimized for collecting uniform data and billing information, they contribute to an overall sense that medicine is moving away from its origins as a profession rooted in compassion, and is moving toward a commercialized entity divorced from humanistic values. This need not be the case, as most providers remain essentially committed to these humanistic values. One hopes that the next generation of electronic medical records will facilitate the expression of these values by making care more efficient rather than stifling them by increasing the administrative burden on providers.

Administrative tasks such as advocating for insurance companies to provide necessary care or seeking specialists willing to accept underinsured patients can contribute to this loss of sense of efficacy and disconnection from meaning. Inasmuch as a sense of meaning keeps providers engaged and satisfied in their work, these tasks that appear less meaningful can be particularly draining and frustrating. Conversely, organizing systems of care to minimize and share less rewarding administrative duties and construct realistic productivity and time demands allows for true connections with patients and contributes

to a sense of meaning and effectiveness. It is common in under-resourced environments for health-care providers to do the work of multiple employees. Physicians find themselves performing phlebotomy, taking vital signs, and calling in medication refills; nurses find themselves making appointments for patients and administering vaccines; and social workers find themselves performing very basic case management tasks. In all of these instances, health-care providers are not working at the tops of their licenses and are likely to become frustrated by the inefficiencies of their system. Workers are unlikely to meet their productivity goals and may work long hours in an attempt to keep up.

Team-based care, in which every person on the team works at the top of his or her level of training, can improve efficiency, distribute responsibility, and create opportunities for everyone on the team to feel valued. Furthermore, providers are most likely to flourish systems with fewer administrative barriers, such as coordinated care systems with clear and functional referral mechanisms, shared medical records, protocols for transfers of care, and rational payment systems that reward quality outcomes and allow innovative systems of care. Reimbursement for telephone or e-mail-based medicine and for nurse, medical assistant, and group visits can allow a care system to become more streamlined and utilize the skills of its team members to best effect.

Teaching and Leadership Roles

Research shows that health-care workers who have administrative or educational roles have lower rates of burnout than those who practice only clinical care.[13] While still serving the primary function of patient care, institutions can offer all health-care workers the opportunity to work with students, teach colleagues or other learners, and participate in special projects. Working with learners often serves as a reminder of the core values that inspired one's entry into the health-care professions and can reinvigorate workers who are struggling to stay connected to those values.

Compensation and Reward

An employee who perceives compensation to be inadequate or unfair is at elevated risk of burnout. Compensation can come in the form of pay or benefits. Often, nonprofit or government organizations have difficulty providing competitive pay for their employees. Expanded employee benefits such as flexible work schedules, generous vacation time, family leave, paid sabbaticals, reimbursement for conferences or continuing education, robust retirement plans, daycare, gym memberships or onsite exercise facilities, workplace wellness activities, employee assistance programs, healthy meals at work, employee-matched retirement plans, overtime compensation, and commuting cost reimbursement are other ways to help employees feel appreciated and well compensated.

In addition to formal compensation, a sense of being rewarded or acknowledged for one's work is also fundamental to work-related well-being. Workers who feel undervalued and under-rewarded have higher rates of burnout. Employers who deliberately reward excellence through public or private acknowledgement, prizes, or even informal thanks can help employees feel recognized and valued.

Flexible Schedules

Another key predictor of burnout is work schedule flexibility. Health-care providers who desire part-time schedules show significantly lower rates of burnout if they have the option to work part time than those who are required to work full time. The same is true of providers who prefer to work full time: if they are able to work the schedule they prefer, they have less burnout than if they are forced to work part time.[14] Part-time health-care providers have been shown to provide the same quality of care for patients in multiple studies and tend to have higher patient satisfaction scores, likely reflecting lower levels of burnout in this population.[15] Offering flexible and accommodating work schedules is an effective way for organizations to prevent burnout among employees.

Teamwork

Health-care providers who experience a high level of "teamness" at work also tend to have lower rates of burnout. Factors that seem to contribute to this experience include working with the same people regularly (e.g., a nurse practitioner always paired with the same medical assistant in clinic); having clear role definitions for each team member; explicitly sharing responsibility for patients among all the team members; and regular two-way communication with every team member. The simple knowledge that there is someone you can trust to help you is reassuring on a difficult day.[16]

Supportive Culture

The ability to discuss difficult cases in a supportive environment is particularly important for people providing care to vulnerable populations. These health-care providers often witness extreme distress and unimaginable tragedies. While they will need to develop strategies outside of work to process the vicarious trauma accumulated at work, they also need support within the workplace. In some settings, regular case conferences can serve this function. In others, encouraging a culture of sharing stories and supporting one another through difficulty is more appropriate. It is particularly important to create an environment in which errors can be discussed thoughtfully and safely. A workplace in which emotions about patient care, fears about bad outcomes, and the joy of good outcomes are given time and attention protects its employees from burnout caused by the difficulties of patient care.[17]

Demographic Factors

Gender

Most studies on gender and burnout demonstrate no difference in rates of burnout between men and women. While women, on average, seem to have higher rates of empathy, which is protective against burnout, they also report feeling less valued by patients, colleagues, and superiors, and they report higher rates of conflict between their work and home life.[18] Men report a greater sense of control at work than women, a protective factor against burnout, but also have higher rates of alexithymia (difficulty identifying their emotions), an independent risk factor for burnout.[19] Altogether, rates of burnout appear similar in men and women, but burnout may take different forms and have different sources in the two groups. For this reason, workplace changes designed to address provider well-being should seek to address the varied needs of different employees.

Marital Status

There are consistently lower rates of burnout among health-care providers who are married. The key feature is probably not marriage itself but a close, stable relationship. Studies show that higher social support overall is associated with lower rates of burnout.[20]

Race and Ethnicity

There are no high-quality data on the impact of race and ethnicity on burnout or compassion satisfaction. Studies of caregivers have historically included primarily white participants, and research in this area is clearly warranted.

Personal Factors

Life Stressors

Health-care workers who are experiencing high levels of stress outside of work are significantly more vulnerable to burnout at work.[21] It is generally impossible to avoid periods of significant life stress. Both the provider experiencing the stress and his or her coworkers can be sensitive to the fact that illness and death, divorce, and other life stressors will likely increase the risk of burnout, at least in the short term. Simple awareness of this fact can often increase people's willingness to offer help, engage in teamwork, and provide a supportive work environment.

Temperament

There is much speculation about the impact of temperament on burnout. Many believe that obsessive personality traits, or "perfectionism," are associated with higher rates of burnout. This has not borne out in studies, where avoidant, dependent, antisocial, and passive-aggressive traits are instead found to correlate with burnout. Being intensely committed and driven does not seem to predict burnout.

Probably the most significant personality feature that appears to put caregivers at risk for burnout is the "alexithymic" personality style.[19] Alexithymia is the inability to recognize or describe emotions. Providers who have difficulty identifying their emotions or the emotions of others have difficulty examining, addressing, and learning from those emotions. Rather than finding deeper meaning in their experiences with patients, they tend to dissociate from them and experience a diminished sense of meaning in their work. Interventions designed to improve providers' emotional awareness and emotional intelligence, such as mindfulness practices, counseling, therapeutic supervision, and group reflection, may improve the prevention of burnout.

COMPASSION SATISFACTION

Compassion satisfaction is a newer concept than burnout, and interest in it is increasing rapidly. As in the field of psychology, where an understanding is developing that we can learn as much from studying positive, healthy states as we can from studying pathological states, the study of worker satisfaction is beginning to shift toward a concerted effort to understand the state that is opposite burnout. It is clear that while some providers experience a great deal of dysphoria associated with working with suffering or trauma, others find meaning and joy in the work. Some seem to experience mild forms of posttraumatic stress while others appear to develop posttraumatic growth (see Chapter 36). What is it that engages people in helping work? What is it that makes this kind of work satisfying, meaningful, and worthy of the very real sacrifices that people make for it?

Compassion satisfaction is defined as the pleasure derived from helping others.[22] It is associated with an increased sense of connection to others, both to coworkers and to those receiving care, in addition to a palpable sense of meaning. Providers who are asked to describe their experience of compassion satisfaction often describe a kind of flow state, or a state of easeful focus on their patient, free from concerns about time, resources, or other distractors. Compassion satisfaction is negatively correlated with burnout and compassion fatigue, and appears to be protective against these states.

PROMOTING COMPASSION SATISFACTION AND PREVENTING BURNOUT

> Andrew is finding little pleasure in his work. He discusses his situation with a trusted colleague. Even though the colleague does not offer concrete solutions, he finds that simply having the conversation makes him feel better and starts him thinking about possible solutions. He recalls activities that have been useful to him in the past in times of struggle, and over the next month, fits them into his busy days. He walks for 10 more minutes on his way to work. He begins

to explicitly reflect upon something he admires about each patient. He requests and receives protected time to collaborate on a project with a group of patients. He finds the new project rewarding and over time, though the stress at home remains, he finds that he feels reconnected with the things he loves about his job.

While there are many studies describing the correlates and risk factors for burnout and a smaller number describing correlates of compassion satisfaction, there are fewer studies of interventions designed to treat or prevent burnout or to promote compassion satisfaction. As a result, recommendations about promoting compassion satisfaction or preventing burnout are largely based on extrapolation from correlational data.

RELATIONSHIP WITH WORK

In order to maintain well-being while working with underserved populations, it is useful to reflect upon and deliberately manage one's feelings about and relationship with work. A sense of meaning in work, a sense of gratitude for one's work, and a commitment to emotional engagement with work all serve to promote compassion satisfaction and make work itself nourishing and enjoyable. Studies show that health-care providers' perceptions of their workplace culture are more correlated with innate factors in the employee than with factors in the workplace. This suggests that self-reflection plays at least as important a role in fostering workplace well-being as interventions designed to change the workplace. For example, physicians who are open to new experiences are more likely to feel that they have control and choice in their work, regardless of the nature of the workplace. Similarly, physicians who take what is called a "deep approach" to work, in which complexity and challenge are welcomed, have lower rates of burnout and higher rates of satisfaction than those who take what is called a "surface approach," characterized by a desire for order and predictability.[23] By deliberately cultivating a deep approach to work, health-care providers have the opportunity to promote compassion satisfaction and protect themselves from burnout.

Reflecting on Core Values and Sources of Meaning

One way to deepen one's relationship with work is to periodically explore the personal values that make the work important and meaningful. This reflection can help re-invigorate a flagging commitment and can turn a joyless task into a creative, meaningful endeavor. Different providers will find that they are driven by different fundamental values. Some are driven by a desire for justice in the world, others by a commitment to kindness, others by a belief in the importance of love, and the list goes on. It can be useful to explore core values with a group of coworkers. It is also useful to take time alone to consider the meaning of one's work and its place in our own personal world views. These explorations often occur spontaneously when colleagues discuss difficult cases together or when health-care workers keep journals about their work experiences. These acts of reflection are supportive of a deepened and nourishing relationship with work.

It is quite common for health-care providers in underserved settings to find that engaging in health advocacy or community engagement efforts serve this purpose for them. By engaging actively in community-driven projects with the community they serve, health-care providers are reminded of the breadth and meaning of their patients' lives, as well as their resilience, creativity, and strength. Similarly, engagement in advocacy or policy-related work often provides a clear reminder of the core values and sense of hope that motivate most health-care providers.

In the field of positive psychology, a distinction is made between "the pleasant life" and "the good life." The pleasant life is a life that prioritizes ease and comfort. It is sometimes referred to as the "frictionless existence." Unfortunately, most people find that the promise of pleasant ease is something of an illusion, given the inevitable vicissitudes and vulnerabilities of human life. Many of us choose instead a life with friction and difficulty, a life that deliberately turns toward suffering and seeks to understand and ameliorate it. This is known as "the good life," a life with meaning, aimed toward some greater good and unafraid of some amount of difficulty. Health-care providers who work in underserved settings have, for the most part, chosen the good life over the pleasant life. This choice requires robust emotional coping skills and self-care practices. It is also enhanced by regular reinvestigation of the underlying values that make it a good life and not merely a difficult one. An examined life enriches a good life.

Promoting Empathy, Compassion, and Emotional Coping Skills

In addition to improving patient outcomes and satisfaction scores, empathy contributes to increased compassion satisfaction. Because empathy can involve sharing in difficult emotions, it must be paired with resilience and emotional intelligence that allows the provider to process the emotions effectively. Alexithymia can negate the positive effect of empathy by preventing caregivers from managing their emotional reactions to work. Health-care providers who develop and maintain genuine emotional connections to their work and have the emotional coping skills to process difficult emotions are more likely to find meaning and joy in their work. This approach can be contrasted with the stance of "detached concern" that has commonly been taught in medical fields but which frequently devolves into dissociation and cynicism.

When a provider chooses to take an empathetic, engaged approach rather than a detached approach, he or she must be prepared for the pain, trauma, and suffering that he or she will witness and absorb. Specific skills such as perspective taking, self-compassion, and identifying one's own emotional needs become critical to maintaining the capacity for empathy.[19] Almost everyone will need help developing and enhancing these skills. This help can come in the form of support groups with other health-care providers, counseling, meditation training, spirituality, artistic engagement, social support, narrative reflection, or many other practices. It behooves a deeply engaged health-care provider to deliberately seek out situations and relationships that enhance his or her emotional resources and allow him or her to remain emotionally available to patients, his or her colleagues, and himself or herself.

SELF-CARE PRACTICES

There is a clear correlation between robust self-care practices, increased levels of compassion satisfaction, and decreased levels of burnout.[24] The approach that an individual takes to self-care will necessarily be unique and personalized. It is unrealistic for any provider to engage in all of the following activities, and health-care providers are instead encouraged to identify the few that are most relevant, realistic, and fruitful for them at any given time.

Health-care providers often find that their needs and capacity for various self-care activities will vary over time, and an effective approach to self-care is one that remains flexible and responsive to the current situation. As an example, a provider might find that for a few years, regular, intense physical exercise is foundational to his or her self-care approach. As the nature of that person's career, stressors, and life changes, he or she may find that another practice such as regular prayer or engaging with a supportive community is more fruitful. Self-care approaches can be divided into practices that occur outside of work and those that are practiced at work.

Outside of Work

Social Support

In some studies, a strong social support network has been found to be the factor most predictive of high levels of compassion satisfaction.[25] Social support can take the form of friend groups, formal support groups, intimate relationships, or spiritual community. Two likely factors that contribute to the protective nature of social support are the ability to share and reflect on the suffering that has been witnessed and, conversely, the opportunity to engage joyfully in relationships in the absence of trauma and suffering. Cultivating social relationships that both allow room for exploring difficulty and offer a meaningful escape is an important self-care strategy for care providers.

Meditation

Meditation has received attention in recent years because it effectively teaches coping skills for managing difficult situations. Studies of regular meditators show increased positive affect, increased ability to pay attention, and increased sense of meaning and connection.[26] Regular meditation has been correlated with higher levels of compassion satisfaction and lower levels of burnout. Interventional studies have also shown that people who are trained in mindfulness meditation are less likely to experience burnout and secondary traumatic stress than those who are not trained.[27] Many health-care providers find initiating a meditative practice difficult, perhaps because they have trained for years to use their minds for problem solving and are used to being highly competent. Consequently, it is typically more effective to study meditation with a teacher or in a class than to try to learn on one's own. Secular meditation courses, such as the well-researched Mindfulness Based Stress Reduction protocol, abound in medicine, making this form of self-care increasingly accessible.

Religious and Spiritual Engagement

There are fewer studies of other forms of spiritual engagement, such as prayer and ritual. Though individual religious and spiritual practices have not been studied, people who describe themselves as religious or spiritually engaged have lower levels of work-related distress.[28] This is no surprise. A provider who witnesses profound suffering and injustice is more likely to turn that experience into personal growth if his beliefs provide hope or give the suffering meaning. Faith that there is fundamental goodness in the world, in whatever form that takes, can be both soothing and invigorating in the face of injustice. While faith and spiritual interest cannot be manufactured, health-care providers can make time and space to pursue their spiritual interests by finding like-minded communities; engaging in regular prayer or ritual; and exploring religious practices, writing, music, and art.

Exercise

Aerobic exercise is known to be an effective treatment for depression, and most people find that their mood improves with regular exercise. Unsurprisingly, regular exercise also correlates with lower levels of burnout. In fact, a small study of a 12-week exercise intervention in people with high burnout scores showed decreased levels of burnout by the end of the intervention.[29] Apart from the issues of burnout and compassion satisfaction, exercise is, as any health-care provider knows, protective of overall health and well-being.

Outside Interests

Enjoying outside interests or hobbies has been correlated with lower levels of burnout. It is less important what the outside interest is than that it is interesting and fun for

the practitioner. Creating art, dancing, gardening, writing, making music, birding, hiking, cooking, the list could go on. Any activity that is creative, joyful, and immersive can be supportive of well-being.

Psychological Practices

There are a number of psychological practices that can be helpful at different times in the life of a health-care provider.[30] Some, like gratitude lists, three-good-things lists, or taking in the good, are designed to help practitioners become more aware of positive aspects of their lives. Others, like controlled breathing and progressive muscle relaxation, help to release tension, while others, like self-compassion pauses and self-affirmations, are designed to support self-respect and care. Psychological counseling, group therapy, and provider support groups can also encourage self-reflection and well-being.

A review of each of these practices is beyond the scope of this chapter, but a brief description of a few practices can give a sense of the options.

Gratitude list—One of the best-studied practices is the gratitude list, which takes advantage of the human tendency to notice what we are looking for. The practitioner is instructed to make a list every evening of three things for which he or she is grateful. Every night, the act is repeated, such that during the day, a habit develops of seeking out things for which to be grateful, subtly changing the experience of the day. Regular gratitude practice is associated with increased positive affect throughout the day and an overall increased sense of well-being and gratitude.[31]

"Taking in the good"—"Taking in the good" is a related practice in which the practitioner trains the mind to experience positive emotions more fully. The practitioner is instructed to notice when something good happens during the day. At that moment, he is instructed to pause and take a moment to really feel the happiness, ease, or other emotion that arises. Our tendency is to let these emotions fly by without feeling them for more than a second or two. People who pause for just 30 seconds to actually take note of and experience these positive emotions notice an increased frequency of positive emotions after only a brief period of practice.

Group or individual support—Many providers benefit from group or individual support beyond these simple self-care practices. Individual therapy can allow providers to reconnect with their core values and examine the meaning of their work in their lives as well as help manage work and life stressors. Group support is available in a variety of formats. Mindfulness-based groups, a meditation-based group format, have robust data to support their use in preventing work-related stress.[27] Balint groups, another group support format in which providers are encouraged to discuss cases and focus on the provider–patient relationship, have been shown in small studies to be effective at improving job satisfaction.[32] Many training programs and some workplaces offer group support in the form of Balint groups or less formalized programs. In addition to cultivating a supportive culture and offering opportunities for self-reflection, these groups help workers feel appreciated and valued by their workplace.

Avoidance of Harmful Behaviors

No discussion of provider well-being is complete without mention of the fact that health-care providers are at increased risk for developing substance use disorders. The heavy use of alcohol or drugs, as a coping mechanism, is ineffective, and can become destructive. Many workplaces offer programs that help providers who develop unhealthy patterns of substance use. Providers who avail these services can see marked improvement in their well-being. A health-care provider who is intoxicated, hung over, or in withdrawal can do serious harm to patients. In addition to drugs and alcohol, many people find themselves using food, television, gambling, or other unproductive activities to cope with work-related stress. Shifting to more productive and fulfilling coping strategies, while not easy, is generally much more satisfying in the long run.

In the Workplace

While self-care outside of work is important to maintaining our well-being, self-care can also be performed in the workplace.

Relationships

The quality of one's relationships with coworkers and patients is predictive of compassion satisfaction and burnout. Health-care providers who feel that they can trust their coworkers and who feel supported by them are more likely to feel satisfied in their work and less likely to burn out.[17] More specifically, providers who feel safe discussing errors and bad outcomes are less likely to be traumatized by those events and more likely to use them for personal and professional growth.

Similarly, providers who have meaningful, rich relationships with their patients are much more likely to derive satisfaction from their work. Taking the time to cultivate these relationships will reap rewards not only for the patient but also for the provider.

Control, Opportunities for Success, and Creative Projects

As described earlier, a sense of control at work is important to maintaining satisfaction and joy in the workplace. In addition, a sense of tangible success can prevent the feelings of inefficacy that characterize burnout. For this reason, seeking out discrete creative projects over which one has some control can be an effective strategy for promoting well-being at work. When a provider is feeling symptoms of burnout, the tendency might be to avoid projects and extra responsibility, but a special project can be exactly what is needed to help renew a sense of control and efficacy in one's work.

Joining a Team

Distinct from personal relationships, membership in a functional team is protective from burnout. While it is incumbent upon management and institutional leaders to create systems that promote teamwork, in the end, the team members themselves make a team function. The culture of health care has historically been one that promoted individual success and heroism over team-oriented work. Learning to share responsibilities, communicate clearly and respectfully, and trust team members can be difficult, but the benefits are significant.

Micro-Breaks

Health-care work can be extremely fast-paced and demanding, and health-care workers sometimes find that hours have gone by without a pause. Deliberately building small breaks into the day can support both physical and mental health at work.[33] This might mean using an online app that rings an alarm every 30 minutes as a reminder to stretch for a moment. It can also mean pausing before each patient encounter to re-set one's emotional state between patients.

Micro-breaks require two components: a trigger and an action. The trigger can be an alarm, or an activity, like opening a door, washing hands, or standing at the threshold of a patient's room. With each trigger, the practitioner commits to pausing and taking an action. The action can be a deep breath, a shoulder shrug to relax the shoulders, visualization, a prayer, a spoken phrase, the setting of intention, or any other action that the practitioner finds useful. As with all self-care practices, micro-breaks are best when they are custom-made and flexible. One practitioner might choose to pause at a patient's door and visualize the residue of previous patient encounters washing away into the ground, while another might take a deep breath every time he or she reaches for the stethoscope and use the moment to remind himself or herself of his or her human connection to the patient.

In addition to these very short pauses, it can also be useful to take slightly longer breaks, on the order of minutes, for brief rejuvenation during the day. These can take the form of a pause to look out a window, stretch stiff muscles, walk up and down a hall, develop a friendship with a colleague, or sit with eyes closed. Even in a busy clinical environment, these tiny moments of stillness can be remarkably helpful and may actually lead to increased productivity.

Specialized Training

Specialized training in the areas that cause the most work-related distress can help prevent burnout and promote compassion satisfaction. As an example, health-care providers who have a high volume of traumatized patients benefit significantly from special training in trauma care.[34] This training provides a context for the suffering that they witness and strategies for working with it effectively, and it has been shown to decrease burnout.

While the data are most robust for training in trauma, it is likely that special training about whatever population a provider works with can increase one's sense of efficacy and therefore prevent burnout. For example, providers whose patients have high rates of addiction report feeling more satisfied in their work when they have learned strategies for helping people manage addiction. If the problems faced by one's patients feel insurmountable, it is very difficult to feel satisfied in one's work. Fortunately, special training in the area of need can often ameliorate the sense that something is insurmountable.

Vacations

There is no substitute for a real vacation. While it is valuable to take small breaks during the day and to replenishing oneself on weekends, it is also necessary to take extended periods of rest periodically.[33] Vacations not only allow a reprieve from work-related stress and opportunities for play and reconnection with friends and family, they can also provide an opportunity to reexamine one's values and the meaning of one's work.

CONCLUSION

For health-care providers who work in challenging environments, self-care is not merely an act of self-preservation, but an act of generosity. Skillful self-care can help us retain the capacity to form genuine relationships with our patients. It allows us to act as models of well-being in our communities, lets us speak honestly about what it means to live in a healthy way, and makes us more effective partners with our patients. Fundamentally, any self-care strategy must be personalized, flexible, and responsive. By learning to identify our own risk factors for burnout and our own promoters of compassion satisfaction, we become proactive agents in maintaining healthy relationships with our vocation.

- Engagement with work is the positive antipode of burnout (BO).
- BO is characterized by emotional exhaustion, cynicism/depersonalization, and lack of personal efficacy.
- Compassion fatigue (CF) is characterized by a gradual loss of the capacity to feel empathy and care.
- Compassion satisfaction (CS) is the experience of pleasure derived from helping others.
- BO and CF are associated with decreased patient satisfaction and worse patient outcomes.

- BO and CF are associated with increased worker turnover, decreased productivity, depression, and suicidality among health-care workers.
- Workplace factors that influence BO, CF, and CS include a sense of control, a sense of shared mission, creative roles, adequate compensation, flexible schedules, teamwork, and a supportive culture.
- Personal factors that influence BO, CF, and CS include demographic factors, life stress, and temperament.
- A relationship with work that is focused on meaning and deep engagement is protective against BO and supportive of CS.
- Empathy and emotional coping skills can be cultivated to promote CS and prevent BO and CF.
- Self-care strategies that prevent BO and support CS include maintenance of supportive relationships, meditation, religious and spiritual engagement, physical exercise, cultivation of outside interests, and practices from positive psychology.
- In order to promote CS and prevent BO and CF, managers and system leaders can promote a sense of control among employees, develop a shared mission for their organization, cultivate teams, provide specialized training, and support employees in taking small breaks and vacations.

Developing a Personal Strategy for Self-Care

- Start by examining your feelings about work and cultivating a healthy, engaged relationship.
  - What makes your work meaningful?
  - What core values are embodied in your work?
  - What is inspiring about your work?
  - How does your work make you feel effective?
  - How does your work make you feel connected?
  - How do you relate to the shared mission of your organization?
- Develop a plan for maintaining your awareness of meaning, inspiration, and compassion satisfaction in your work. Possible strategies include the following:
  - Regular written reflection
  - Reflective conversations with colleagues or friends
  - Other forms of reflective expression such as painting, dancing, or music
  - Participation in community-engaged activism, community building, or advocacy
  - Taking on a creative project or a teaching role at work
- Develop a support system at work.
  - Cultivate meaningful relationships with coworkers.
  - Discuss difficult cases and provide opportunities for others to discuss their difficulties without feeling judged.
  - Discuss your shared mission with coworkers and be open to new ways to achieve that mission.
  - Share work with team members—help them when they need help and let them help you.
- Commit to activities that are rejuvenating for you and calendar them with the same importance as other obligations in your life. Choose activities that bring you joy, not activities that feel like more obligation. Examples include the following:
  - Physical exercise, including dance, yoga, running, swimming, and sports
  - Hobbies and creative activities
  - Micro-breaks
  - Vacations
  - Time with loved ones
  - Spiritual or religious practices and gatherings
- Cultivate your capacity for empathy and joy. Deliberately train your mind in the direction you would like it to grow. Strategies include the following:
  - Learn and practice meditation, either seated meditation or a moving meditation like yoga or Tai Chi.
  - Work with a counselor, therapist, or mentor.
  - Notice, acknowledge, and respect difficult feelings that arise in the course of work. Learn to feel them fully and, eventually, to grow from them.
  - Choose a practice to cultivate the state you feel you most need to cultivate:
    - Make gratitude lists.
    - Practice stepping back to see the big picture and take in a larger perspective.
    - Pause to notice and absorb good feelings when they happen.
    - List three good things that happen every day.
    - Send compassion to yourself regularly. Consider setting a timer to remind yourself.
    - Send compassion or thoughts of kindness to others the same way.
- Examine your use of drugs, alcohol, food, gambling, television, and computers, and avoid using them as your primary escape mechanism. If you find that you do not have control of alcohol or drug use, reach out for help from professionals or from people in recovery.

DISCUSSION QUESTIONS

1. How does working with vulnerable populations influence your personal need for self-care?
   a. Are there challenges that are unique to working with these populations?
   b. Are there features of working with vulnerable populations that help you remain engaged in your work?
2. Burnout among health-care providers is correlated with lower rates of patient adherence to recommendations, slower surgical healing time, and decreased patient satisfaction. How might burnout lead to these outcomes?
3. Have you experienced compassion satisfaction? What personal factors, patient factors, and work factors promote compassion satisfaction in your own work?

RESOURCES

The University of Massachusetts Center for Mindfulness Web site contains many resources describing mindfulness practice, its impact, and other tools for finding balance in the medical life. Training programs are offered. http://www.umassmed.edu/cfm/.

Commonweal is an organization that runs programs designed to support health-care providers in treating or avoiding burnout and developing compassion satisfaction. www.commonweal.org.

An extensive resource describing self-care practices. The "Psychological Practices" section describes in depth many specific practices that can be used to cultivate helpful mental and emotional habits. http://yourskillfulmeans.com/.

A Web site developed by Dike Drummond, MD, focused on strategies for maintaining wellness while working in health care. http://www.thehappymd.com/.

Pulse: Voices at the Heart of Medicine. This is an online medical literary journal. Subscribers can sign up to receive a weekly e-mail containing a new piece of short writing about giving or receiving health care. It is an easy way to inject a small bit of humanistic reflection into every week. http://pulsevoices.org/.

Videos:

Goldman, Brian. Doctors make mistakes. Can we talk about that? http://www.ted.com/talks/brian_goldman_doctors_make_mistakes_can_we_talk_about_that

Brian Goldman discusses an aspect of medical culture, shame at making mistakes, that isolates and burns out health-care providers.

Zubin Damania. Are zombie doctors taking over America? http://www.tedmed.com/talks/show?id=34752

Zubin Damania discusses the factors that lead to burnout in primary care and envisions a radical transformation in medical systems.

Books:

Remen RN. Kitchen Table Wisdom. Berkley Publishing Group, 1996.

Stone J, Reynolds R. On Doctoring. Simon & Schuster, 1991.

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