

## PART I

# Impact of the Disease to the Individual and Family

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## CHAPTER 1

# Chronicity

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The prevalence of chronic disease on a worldwide basis is similar to, if not greater than, that in the United States. The World Health Organization (WHO) views chronic disease as a silent pandemic spreading to all parts of the world. The WHO uses the term noncommunicable disease (NCD) to denote chronic disease. Noncommunicable diseases are responsible for the deaths of 40 million people every year, which amounts to 70% of the total deaths worldwide. Cardiovascular disease, cancer, respiratory diseases, and diabetes account for 81% of all NCD deaths (WHO, 2017). Twenty percent of chronic disease deaths occur in high-income countries, whereas the remaining 80% occur in low- and middle-income countries (WHO, 2013a).

Addressing the issues of chronic illness is a global challenge. The global pandemic of chronic disease has emerged in tandem with the changing demography of the world population. Throughout the world, the birth rate exceeds the death rate; in addition to having better access to treatment, more people are living to advanced ages, creating a phenomenon of “global aging.” These epidemiologic transitions are dynamic, wherein some diseases may disappear while others recur; for example, infectious diseases are reemerging in high-income countries as

bacteria develop resistance to antibiotics. Whereas many healthcare professionals might consider the increase in chronic disease to be largely attributable to an aging population, the issue is much more complex. Demographic, socioeconomic, technologic, cultural, environmental, and biologic changes also affect the incidence of chronic disease.

Chronic diseases are common, costly, and debilitating, but often they may be prevented. Four health-damaging, but modifiable, behaviors—tobacco use, insufficient physical activity, poor nutrition, and excessive alcohol use—are currently responsible for much of the illness, disability, and premature death related to chronic disease (Centers for Disease Control and Prevention [CDC], 2015). One-half of the disability prevalence among U.S. adults in 2013 could be attributed to the presence of at least one of the modifiable factors. Individual risk factors, smoking, obesity, and hypertension—in that order—were the most consequential (Mehta, Patel, Ali, & Narayan, 2017).

## ► Introduction

In 2012 it was estimated that one of two adults in the United States—117 million people—had

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one or more chronic health conditions, with one in four adults having two or more chronic health conditions (CDC, 2016a). Seven of the top 10 causes of death in 2014 were chronic diseases. Heart disease and cancer, together, accounted for nearly 48% of all deaths (CDC, 2017). The leading causes of death in the United States in 2014 were as follows (CDC, 2017):

- Heart disease
- Cancer
- Chronic lower respiratory disease
- Accidents
- Cerebrovascular disease
- Alzheimer's disease and other dementias
- Diabetes
- Influenza and pneumonia
- Kidney disease
- Suicide

The mortality rate of cancer has surpassed that of heart disease in a number of states. In 2000, there were only two states where cancer was the leading cause of death; in 2014, there were 22 (Heron & Anderson, 2016).

In 2013 (the most current data available) healthcare costs of chronic disease amounted to 86% of the total U.S. healthcare costs, which were \$2.9 trillion at that time (CDC, 2016a). The CDC leads U.S. efforts to prevent and control disease and their risk factors through the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). Fast facts from the NCCDPHP indicate that prevention makes a difference.

- Tobacco prevention and control is one of the “best buys in public health.” States with strong tobacco control programs see a \$55 return on every \$1 investment, mostly from avoiding costs of treating smoking-related illness.
- Every \$1 spent to fluoridate a community water system saves about \$38 each year from fewer cavities needing to be treated.
- The annual cost of offering the National Diabetes Prevention Program is about \$500 per participant, which is much lower than the \$7,900 spent on diabetes care per

patient each year for those who progress to type 2 diabetes.

- A 13% reduction in the number of people with uncontrolled hypertension (4.7 million) would save the healthcare system \$25.3 billion per year in averted disease costs. (CDC, 2016b).

From 1990 to 2010, the United States made significant progress in improving health. However, morbidity and chronic disability now account for nearly half of the U.S. health burden, and improvements in population health have not kept pace with advances in population health in other wealthy nations (U. S. Burden of Disease Collaborators, 2013).

## Disease Versus Illness

Although the terms *disease* and *illness* are often used interchangeably, there is a distinct difference between them. “Disease” refers to the pathophysiology of a condition. “Illness,” in contrast, is the human experience of a disease and refers to how the disease is perceived, lived with, and responded to by individuals, their families, and healthcare professionals. The pathophysiology of a disease predominates care; however, to provide holistic care, one needs to recognize and understand the illness experience of the patient and family.

From the perspective of the patient:

*It is Sunday, 2:08 a.m. I am wheeled into a sterile white examination room, obviously used for “codes,” patients like me, deemed to be in serious trouble. I look at the reinforced glass in the windows separating my room from the other side. The curtains are drawn and I cannot see out, but on my side I can read the words on the glass, changing with each window:*

*O<sub>2</sub> \_\_\_ L-m \_\_\_ by \_\_\_  
Medication Dose Time  
IV Fluid Rate  
Defibrillation*

*Beth puts her arms around me and holds me. She doesn't deserve this, I think. Why*

*must she go through all of this again?*  
(Hsi, 2004, pp. 164–165)

From the perspective of the caregiver:

*Today is the 19th day in a row that Randy has seen a healthcare professional, and actually a couple of those days, he saw two different ones on the same day. It's either radiation therapy, receiving IV fluids and/or replacement potassium, an IV antibiotic for a resistant infection, receiving blood as an outpatient, persistent vomiting, . . . something every day. Will this ever stop? Will we ever have a normal life again? Right now I don't even remember what normal is.*

—Pamala

Patient and family stories chronicle the illness experience. Patients and families are the ones who are perceiving and living with the chronic disease. Healthcare professionals play a part in that experience; however, the primary players are the patient and family.

The focus of this text is on the chronic illness experience of individuals and families. Although specific disease processes may have unique physical characteristics, the psychosocial concepts discussed in this book are experienced by many patients and families with chronic disease. Even though chronic disease cannot be cured, nursing can have an impact on the illness experience with care versus cure.

## Defining Chronic Illness

Defining chronic illness is complex. An early definition by the Commission on Chronic Illness included impairments and deviations from the normal that had one or more of the following characteristics: permanency; residual disability; nonpathologic alteration; and required rehabilitation or a long period of supervision, observation, and care. Disability may depend not only on the kind of condition and its severity, but also

on the implications it holds for the person. The degree of disability and altered lifestyle—part of traditional definitions—may relate more to the *patient's perceptions and beliefs* about the disease than to the disease itself.

Long-term and iatrogenic effects of some treatment may constitute chronic conditions in their own right. Of particular note are the chemotherapies and radiation therapy treatments for cancer. Studies have demonstrated that some of these life-saving treatments that occurred many years ago may lead to the development of a new cancer.

Although definitions of chronic disease are important, from a nursing perspective we are far more interested in how the disease affects the patient and family from a psychosocial perspective. What is the illness experience of the patient and family? Perhaps the onus of defining chronic illness—and similarly, quality of life—should be placed on the patient, as only the patient understands and “knows” the illness experience. However, that aside, the following definition of chronic illness is offered:

*Chronic illness is the lived experience of the individual and family diagnosed with chronic disease. The individual's and family's values impact their perceptions and beliefs of the condition and thus their illness and wellness behaviors. Their values are influenced by demographic, socioeconomic, technological, cultural, and environmental variables. The lived experience is “known” only to the individual and family. (Larsen, 2016, pp. 5–6)*

## ► Impact of Chronic Illness

The impact and interventions cited in this chapter examine chronic disease from an aggregate perspective, using a public health lens to view chronic disease and potential interventions.

## The Older Adult

Although chronic diseases and conditions exist in children, adolescents, and young and middle-aged adults, the bulk of these conditions occur in adults age 65 years and older. Since 1900, the percentage of the U.S. population made up by older Americans has tripled. According to *A Profile of Older Americans: 2015*, between 2004 and 2015, the population age 60 and older increased 34%, from 49.8 million to 66.8 million. By 2060, it is projected there will be 98 million adults in the United States who are older than 65 years (Administration on Aging, 2016).

It has been suggested that the United States is not investing sufficiently in keeping people healthy late in life (Rowe, Fulmer, & Fried, 2016). Advances are needed in four areas to improve the health and well-being of older persons, especially those with multiple chronic conditions (MCCs): (1) enhancing care delivery for chronic conditions; (2) strengthening the elder care workforce; (3) fostering social engagement in late life; and (4) strengthening advanced illness and end-of-life care (p. 1644).

The report *State of aging and health in America 2013* (CDC, 2013) provides a snapshot of the impact of chronic illness on older adults. With two of every three older Americans having MCCs, the need for action is apparent. The National Report Card on Healthy Aging reports on 15 indicators of older adult health, 8 of which are identified in *Healthy People 2020*. On a positive note, older adults have met six of the *Healthy People 2020* targets—those dealing with leisure-time physical activity, obesity, current smoking, taking medications for high blood pressure, mammograms within the past 2 years, and colorectal cancer screenings. However, three areas need improvement in this population: receiving a flu vaccine, receiving pneumonia vaccine, and up-to-date preventive services. Consequently, *State of aging and health in America 2013* lists several calls to action to improve the health and well-being of older adults:

- Developing a new Healthy Brain Initiative Road Map
- Addressing aging and health issues among the lesbian, gay, bisexual, and transgender (LGBT) community
- Using data on physically unhealthy days to guide interventions
- Addressing mental distress among older adults
- Monitoring vaccination rates for shingles (CDC, 2013)

## High-Need, High-Cost Patients

Meeting the needs of high-need, high-cost patients is a challenge for healthcare providers. High-need, high-cost patients, who experience a variety of complex medical conditions, have limitations in the ability to care for themselves; although they are only 5% of all patients, they account for 50% of healthcare spending (Blumenthal & Abrams, 2016). These patients are also more likely to experience less quality and safety in their care (p. 711). In addition, MCC patients are likely to have unmet social needs that may exacerbate their medical conditions.

Older adults will access—if their socioeconomic status permits—an acute care system. How will the needs of these aging adults affect the healthcare delivery system in this country?

## National Healthcare Quality and Disparities Report

Late identification of persons with chronic disease, due to access issues, leads to poor outcomes, more complications for the individual, and greater healthcare expenditures. These individuals may be young, middle-aged, or older, but their outcomes are similar. As chronic disease requires long-term care, the need for quality care and continued access to that care is essential. If there is poor quality of care or limited access, health outcomes tend to be poor.

It must also be noted that social determinants, the conditions in which people live, learn, work,



play, and worship, affect health and produce disparities. These determinants include poverty, lack of access to high-quality education or employment, unhealthy housing, unfavorable work and neighborhood conditions, and exposure to neighborhood violence (Thornton et al., 2016).

The National Healthcare Quality and Disparities Report (Agency for Healthcare Research and Quality [AHRQ], 2016) is an indicator of how the United States is performing regarding quality of care and health disparities. The statistics on quality and access to care are vitally important to individuals across the country.

Since 2003, the Agency for Healthcare Research and Quality (AHRQ) has reported on progress and opportunities for improving healthcare quality and reducing healthcare disparities. As in prior years, the findings from the National Healthcare Quality Report (NHQR) and the National Healthcare Disparities Report (NHDR) have been integrated into a single report to reinforce the need to consider concurrently the quality of health and disparities across populations.

To obtain high-quality care, individuals must first gain entry into the healthcare system. Measures of access to care tracked in the Quality and Disparities Report include having health insurance, having a usual source of care, encountering difficulties when seeking care, and receiving care as soon as wanted. Historically, Americans have experienced variable access to care based on race, ethnicity, socioeconomic status, age, sex, disability status, sexual orientation, gender identity, and residential location (AHRQ, 2016). The latest report reveals the following:

- People in poor households had worse access to care than people in high-income households on all access measures.
- Hispanics had worse access to care than Whites for two-thirds of access measures.
- Blacks had worse access to care than Whites for about half of access measures.
- Asians, American Indians, and Alaska Natives had worse access to care than Whites for about one-third of access measures.

Similarly, quality of health care has varied based on race, ethnicity, socioeconomic status, age, sex, disability status, sexual orientation, gender identity, and residential location. Measures of healthcare quality encompass a broad array of services, including prevention, emergency treatment, behavioral health care, and chronic disease management, and in a variety of settings such as medical offices, health centers, emergency departments, dialysis centers, hospitals, mental health and substance abuse treatment facilities, nursing homes, hospices, and home health (AHRQ, 2016). Data from the latest report include the following:

- People in poor households received worse care than people in high-income households for about 60% of quality measures.
- Blacks, Hispanics, American Indians and Alaska Natives received worse care than Whites for about 40% of quality measures.
- Asians received worse care than Whites for about 20% of quality measures.

In a survey of 11 countries, Osborn and colleagues (2016) compared adults in the United States with adults in 10 other countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom) on issues of access and affordability of health care. Relative to other countries, the healthcare system in the United States performs poorly in meeting several population health goals. Factors affecting access in the United States included high out-of-pocket spending and lack of available after-hours care, coordination of care, and management of chronic illness (p. 2333). The United States remains an outlier among high-income countries in ensuring access to health care. Overall, the Netherlands performed at the top of the 11 countries on most measures of access, engagement, and coordination (Osborn, Squires, Doty, Sarnak, & Schneider, 2016).

## Healthcare Consumer

Medical expansion continues in the United States; whereas healthcare expenditures were 5.1% of

the gross domestic product (GDP) in 1960, they were 17.8% in 2015. Some of this expansion is due to the role of consumers. Zheng (2015) suggests that in the course of medical expansion, consumers' health knowledge and literacy have increased substantially, and this trend has led to a lower tolerance for disease and discomfort and a greater demand for medical solutions. Several decades ago Illich (1975) suggested that any personal responsibility for suffering, pain, and impairment has been removed and has created dependence on health care. Medical expansion and an increase in healthcare expenditures have not led to better subjective health. Zheng (2015) analyzed trends in self-rated health across 28 countries participating in the World Values Survey or the European Values Study since 1981, and did not find significant improvements in subjective health (p. 36).

Zheng (2015) offers four reasons, from his work and others, as to why medical expansion has not been accompanied by increased subjective health. First, more diseases are being discovered or created during periods of medical expansion; for example, a change in the way autism was diagnosed led to an increase in autism prevalence in California between 1992 and 2005. Second, individuals are being exposed to more aggressive screening and diagnostic tests, which increase the likelihood of being diagnosed with a disease. Third, medical expansion may increase people's expectations for health, and people may believe that they suffer from health issues when their expectations are not met. Lastly, medical expansion causes people experiencing health or even nonhealth problems to subordinate their lives to medical institutions and treatments. Once in that system, patients are subject to "sick role expectations" (see Chapter 2) and stigma that contribute to social withdrawal, reduction of activities, increased dependency, and the loss of self-esteem and self-efficacy and sense of control (p. 36).

The population over the age of 65 continues to grow significantly owing to the influx of baby boomers (individuals born between 1946 and 1964). The newest group of seniors is the most

ethnically and racially diverse of any previous generation. Members of this well-educated, consumer-driven generation want information about their conditions and all treatment options. They question their healthcare professionals and do not blindly accept healthcare advice and treatment options. These consumers want the ability to say "yes" or "no" to treatment options.

William Frist, a heart and lung transplant surgeon and former U.S. Senate majority leader and senator from Tennessee, has spoken about two influences on health care today—namely, the rapid ascent of the newly empowered consumer with knowledge that can affect his or her health and advances in information technology (IT) (Frist, 2014). Neither of these changes were significant drivers of health care even 10 years ago; Frist, however, believes that the "empowered consumer and rapidly advancing health IT will channel our chaotic, fragmented, and wasteful health care sector toward a more seamless, transparent, accountable and efficient system" (p. 191).

The biggest driver of health status is individual health behavior. Only 10–15% of an individual's health status is attributable to the healthcare service he or she receives (Schroder, 2007). The rest is determined by behavior; genetics; and social determinants, which include living conditions, access to food, and educational status (Frist, 2014). The number of individuals with chronic disease is climbing. To avert those conditions for millions of others who are at risk, healthcare systems must make healthy choices easy for individuals to accept into their daily lives.

## Financial Impact

Total U.S. healthcare spending increased by 5.8% to \$3.2 trillion or \$9,990 per person in 2015 as compared with data from 2014 (Martin, Hartman, Washington, Catlin, & National Health Expenditure Accounts Team, 2017). Following five consecutive years of historically low growth from 2009 to 2013, health spending growth accelerated in 2014 (up 5.3%) and in 2015 (up 5.8%). Coverage expansion that began in 2014,



as a result of the Affordable Care Act, continued to affect healthcare spending growth in 2015 (p. 166). This was accompanied, however, by a slowdown in overall economic growth in the country, from 4.2% in 2014 to 3.7% in 2015. The increase in total healthcare spending in 2015 was primarily driven by spending on private health insurance, hospital care, and physician and clinical services, although at a slower rate than in 2014 (p. 167). Martin and colleagues (2017) note several important findings:

- Total expenditures for private health insurance reached \$1.1 trillion and increased 7.2% from 2014. Private health insurance continues to be the largest payer of health care in the United States, and accounts for 33% of total healthcare spending (p. 171).
- Growth in prescription drug spending, up 9%, was more than for any other service in 2015. Spending on new brand-name medications continued to drive overall growth in prescription drug spending.
- Healthcare spending is projected to increase as a share of the overall economy during the next 10 years and will be influenced by the aging population, changing economic conditions, and faster medical price growth (p. 175).
- In 2014 and 2015, spending by the federal government on health care grew faster than spending by any other sponsor, increasing 8.9% in 2015 after an 11% increase in 2014.

The American Heart Association (AHA) predicts that cardiovascular (CV) disease costs will reach \$1.1 trillion by 2035. If left unchecked, CV disease will affect 45% of the total U.S. population. The AHA had estimated in 2011 that the number of people with CV disease would reach 100 million by 2030. Unfortunately that prediction was reached in 2015, 15 years earlier than predicted (AHA, 2017).

In the United States in 2008, the top 10 costliest medical conditions, in rank order, were the same for both men and women age 18 years and older: (1) heart disease, (2) cancer, (3) mental disorders, (4) trauma-related disorders,

(5) osteoarthritis, (6) asthma, (7) hypertension, (8) diabetes, (9) back problems, and (10) hyperlipidemia (Soni, 2011). However, the highest per-person mean expenditures were in cancer for both men and women—\$4,873 and \$4,484, respectively. These data indicate that chronic disease is the nation's greatest healthcare problem and the number one driver of health care today. With the aging population and the advanced technologies that help clients to live longer, these costs will only increase.

Data from the National Health Interview Survey (NHIS) from 2012 found that one in four families experience a financial burden paying for medical care. One in 10 persons in a family are unable to pay anything toward health care (Cohen & Kirzinger, 2014). Additionally, one in three families with children experience a financial burden from medical care.

The Organization for Economic Cooperation and Development (OECD) annually tracks and reports on more than 1,200 health system measures across 30 industrialized countries. The United States continues to differ markedly from other countries examined in the OECD report. Using data from the OECD Health Statistics, 2014 (OECD, 2015a), the annual health expenditure per capita (incorporating both public and private expenditures) for an individual in the United States was \$8,745 (the 2015 amount was \$9,990, as mentioned previously) and ranked number one for healthcare spending. The average health expenditure per capita among OECD countries was \$4,791.

Compared with other OECD countries, the United States has fewer physicians per capita (2.5 per 1,000 population compared with the OECD average of 3.2), more nurses (11.1 per 1,000 population compared with the OECD average of 8.8), and fewer hospital beds (3.1 per 1,000 population compared with the OECD average of 4.8). This decline in U.S. hospital beds coincides with the reduction in the length of stays in hospitals and an increase in day surgeries.

While life expectancy at birth in the United States was 1½ years greater than the OECD average in 1960, it is now, at 78.7 years, almost

2 years less than the OECD average of 80.5 years, Japan, Spain, and Switzerland lead a group of eight OECD countries where life expectancies exceed 82 years (OECD, 2015b). The United States ranks 27th in life expectancy out of the 34 OECD countries.

One health risk factor—obesity—has affected any increase in life expectancy. The obesity rate among adults in the United States between 2011 and 2014 was 36.5%, up from 15% in 1978 (Ogden, Carroll, Fryar, & Flegal, 2015). This is the highest rate among all OECD countries. The average obesity rate for the 15 OECD countries for which data were available was 22.8%.

One positive note is that smoking in the United States has decreased significantly. The rate in the United States decreased from 33.5% in 1980 to 14% in 2012. Only Mexico, Sweden, and Iceland have lower rates of smoking (OECD, 2015b).

## ► Interventions

Chronic disease is an issue that is all encompassing, such that interventions from a variety of sources are needed to make a difference. What is the role of the registered nurse (RN) in the care of clients with chronic disease? Professional education, evidence-based practice, and legislation affect any potential interventions. Lastly, paradigms from the Centers for Disease Control and Prevention, the Health and Medicine Division (formerly the Institute of Medicine), and the World Health Organization address chronic disease and ways to mitigate its impact.

## The Role of Nursing

The 2015 National Nursing Workforce Survey demonstrated that with the current trend, there will be sufficient numbers of new RNs entering the profession to offset concerns about a potential nursing shortage due to retirements (Halpern, 2016). The average RN is 48.8 years old, indicating that the aging of the RN workforce may

be slowing down, as the average age in 2013 was 50 years. Ethnic minorities accounted for 19.5% of the workforce in both 2013 and 2015, and accounted for higher proportions of younger and recently licensed RNs (p. 17). Data also revealed that RNs are more highly educated than ever before.

With a sufficient number of RNs, the possibilities are endless of how they might work with individuals with chronic disease. For the past few years, there has been talk about expanding the role of the RN. It is no secret that primary care in the United States is in need of transformation. The Affordable Care Act (ACA), also known as Obamacare, which emphasized the importance of primary care, has enabled millions of Americans to seek care, many of those individuals having at least one chronic condition. Strengthening the core of primary care service delivery is key to achieving the Triple Aim: improved patient care experiences, better population health outcomes, and lower healthcare costs (Josiah Macy Jr. Foundation, 2016). The Macy Foundation asks, “Who can help alleviate the pressures on primary care?” An available resource is the 3.1 million RNs. Because RNs are not directly reimbursable under the traditional fee-for-service model, new payment models will need to be developed to facilitate primary care teams that include RNs.

The California Healthcare Foundation (2015) lists 12 strategies to enhance the role of the RN in primary care. Two of the strategies clearly speak to the role of the RN in chronic disease: provide patients with RN-led chronic care management visits and employ RNs’ skills to care-manage patients with complex health care needs (p. 6).

Bodenheimer and Bauer (2016) explain that nurse practitioners (NPs) and physician assistants (PAs) are increasingly fulfilling the roles in chronic care that physicians once occupied. A large part of that trend is the decreasing number of primary care physicians. Many are retiring each year and are not being replaced. In addition, physicians tend not to practice in rural areas, unlike NPs and PAs. RNs could be

an important part of the healthcare team by serving as chronic care managers. An expanded role for RNs indicates that additional training/education would be necessary (Bodenheimer & Bauer, 2016; California Healthcare Foundation, 2015; Josiah Macy Jr. Foundation, 2016).

## Professional Education

One of the challenges in chronic disease care and management is educating healthcare professionals about providing care tailored to those with chronic disease. The differences are vast between caring for a person with an acute illness on a short-term basis and caring for a person with a chronic condition over the long haul. WHO developed a document outlining the steps to prepare a healthcare workforce for the 21st century that can appropriately care for individuals with chronic conditions. The WHO document calls for a transformation of healthcare training to better meet the needs of individuals with chronic conditions. This document, *Preparing a Healthcare Workforce for the 21st Century: The Challenge of Chronic Conditions* (WHO, 2005), has the support of the World Medical Association, the International Council of Nurses, the International Pharmaceutical Federation, the European Respiratory Society, and the International Alliance of Patients' Organizations.

The competencies delineated by WHO (2005) were identified through a process that included an extensive document/literature review and international expert agreement (p. 14). All competencies were based on addressing the needs of patients with chronic conditions and their family members from a longitudinal perspective, and focused on two types of "prevention" strategies: (1) initial prevention of the chronic disease and (2) prevention of complications from the condition (p. 18). The five competencies include patient-centered care, partnering, quality improvement, information and communication technology, and public health perspective (**BOX 1-1**). At first glance, the competencies might not seem unique. However,

### BOX 1-1 WHO Core Competencies

#### Patient-Centered Care

Interviewing and communicating effectively  
Assisting changes in health-related behaviors  
Supporting self-management  
Using a proactive approach

#### Partnering

Partnering with patients  
Partnering with other providers  
Partnering with communities

#### Quality Improvement

Measuring care delivery and outcomes  
Learning and adapting to change  
Translating evidence into practice

#### Information and Communication Technology

Designing and using patient registries  
Using computer technologies  
Communicating with partners

#### Public Health Perspective

Providing population-based care  
Systems thinking  
Working across the care continuum  
Working in primary healthcare-led systems

Reprinted from *Preparing a health care workforce for the 21st century: The challenge of chronic conditions*. Geneva, Switzerland: World Health Organization, p. 20., Copyright 2005.

in an acute care-oriented healthcare delivery system, these concepts are not as prominent. Clients move in and out of the care system quickly, and there is less need for implementation of these concepts.

## Evidence-Based Practice

The evidence-based practice movement had its beginnings in the 1970s with Dr. Archie Cochrane, a British epidemiologist. In 1971, Cochrane published a book, *Effectiveness and efficacy: Random reflections on health services*, that criticized physicians for not conducting

rigorous reviews of evidence to ensure that they were making appropriate treatment decisions. Cochrane was a proponent of randomized controlled trials (RCTs), and in his exemplar case noted that thousands of low-birth-weight premature infants died needlessly. At the same time, there were several RCTs that had been conducted on the use of corticosteroid therapy to halt premature labor in pregnant women, but the data had never been reviewed or analyzed. After review, these studies demonstrated that corticosteroid therapy was effective in halting premature labor and resulted in a decrease in infant deaths due to prematurity. The result of Cochrane's call for systematic reviews of the literature was the establishment of the Cochrane Collaboration in Oxford, England, in 1993. The Cochrane Collaboration has 52 review groups composed of individuals around the world who share an interest in developing and maintaining systematic reviews in particular areas (Chan, 2013). The Cochrane Collaboration also hosts the Cochrane Library, which is a sophisticated collection of databases containing current, high-quality research that supports practice.

As healthcare professionals examine the evidence to improve the care of their clients, there are a number of sources for reference. The following agencies and organizations are examples of some of the resources available:

- Agency for Healthcare Research and Quality (AHRQ) ([www.ahrq.gov](http://www.ahrq.gov))
- *Clinical Evidence* ([www.clinicalevidence.com](http://www.clinicalevidence.com))
- Cochrane Library ([www.thecochranelibrary.com](http://www.thecochranelibrary.com))
- Joanna Briggs Institute ([www.joannabriggs.org](http://www.joannabriggs.org))
- National Guideline Clearinghouse ([www.guideline.gov](http://www.guideline.gov))
- Task Force on Community Preventive Services ([www.thecommunityguide.org](http://www.thecommunityguide.org))
- U.S. Preventive Services Task Force ([www.ahrq.gov/clinic/uspstfab.htm](http://www.ahrq.gov/clinic/uspstfab.htm))
- Veterans Evidence-Based Research Dissemination Implementation Center (VERDICT) ([www.verdict.research.va.gov](http://www.verdict.research.va.gov))

## Legislation

On March 21, 2010, President Barack Obama signed legislation to reform the U.S. healthcare delivery system. The Patient Protection and Affordable Care Act (ACA) and the Health Care and Education Reconciliation Act expanded health insurance coverage to individuals who were not previously covered by any health plan through the implementation of individual and employer mandates as well as through expansion of federal and state programs such as Medicare and Medicaid. According to the Congressional Budget Office (CBO), an estimated 32 million additional individuals will be covered by 2019 (Albright et al., 2010).

Instead of creating a new healthcare financing system, in the same way that Medicare and Medicaid were created in the 1960s, the ACA attempted to build on the current system (Jost, 2014). Although building on “what was” was intended to make it easier for implementation, it actually made it much harder. Also, the roll-out of the federal marketplace for healthcare policies on October 1, 2013, was a disaster. Multiple technical and political failures became apparent in the design of the defective, nonfunctional [healthcare.gov](http://healthcare.gov) website. In going forward, one of the challenges of the ACA will be to ensure that its benefits become apparent quickly and dramatically enough to offset the problems (Jost, 2014, p. 10).

The ACA addresses the real problem of millions of uninsured Americans, and if it accomplishes its goal, it will be considered successful. However, the longevity of the ACA is in question. The Trump administration and the Republican-led Congress attempted to pass a new healthcare bill and repeal the ACA in March 2017; however, opposition to the bill was great, even by some Republicans, and it did not come to a vote in Congress. There is continued talk about repealing the ACA.

## Healthy People 2020

*Healthy People* provides science-based, 10-year national objectives for improving the health

of all Americans (<http://www.healthypeople.gov>). In the 2020 document, there is a renewed focus on identifying, measuring, tracking, and reducing health disparities through a determinants-of-health approach. The mission of *Healthy People 2020* is fivefold:

- Identify nationwide health improvement priorities.
- Increase public awareness and understanding of the determinants of health, disease, and disability and the opportunities for progress.
- Provide measurable objectives and goals that are applicable at the national, state, and local levels.
- Engage multiple sectors to take actions to strengthen policies and improve practices

that are driven by the best available evidence and knowledge.

- Identify critical research, evaluation, and data collection needs.

The topic areas and objectives of *Healthy People 2020* are based on four overarching goals: (1) attain high-quality, longer lives free of preventable disease, disability, injury, and premature death; (2) achieve health equity, eliminate disparities, and improve the health of all groups; (3) create social and physical environments that promote good health for all; and (4) promote quality of life, healthy development, and healthy behaviors across all life stages. Topic areas of *Healthy People 2020* are listed in **TABLE 1-1**. Many of the topics relate to chronic disease or prevention of chronic disease.

**TABLE 1-1** Topics of *Healthy People 2020*

Access to health services	Heart disease and stroke
Adolescent health	Human immunodeficiency virus (HIV) infection
Arthritis, osteoporosis, and chronic back conditions	Immunization and infectious diseases
Blood disorders and blood safety	Injury and violence prevention
Cancer	Lesbian, gay, bisexual, and transgender health
Chronic kidney disease	Maternal, infant, and child health
Dementias, including Alzheimer's disease	Medical product safety
Diabetes	Mental health and mental disorders
Disability and health	Nutrition and weight status
Early and middle childhood	Occupational safety and health
Educational and community-based programs	Older adults
Environmental health	Oral health
Family planning	Physical activity
Food safety	Preparedness
Genomics	Public health infrastructure
Global health	Respiratory diseases
Health communication and health information technology	Sexually transmitted diseases
Healthcare-associated infections	Sleep health
Health-related quality of life and well-being	Social determinants of health
Hearing and other sensory or communication disorders	Substance abuse
	Tobacco use
	Vision

U.S. Department of Health and Human Services. Office of Disease Prevention and Health promotion. *Healthy People 2020*. Washington, DC. Available at <http://healthypeople.gov/2020/topicsobjectives2020/default.aspx>.



## CDC's National Center for Chronic Disease Prevention and Health Promotion

The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), a center within the CDC, is at the forefront of the nation's efforts to promote health and well-being through prevention and control of chronic disease. The interventions of the NCCDPHP are critical in supporting the nation's public health infrastructure as it works with healthcare providers, public health professionals, educators, and policy-makers. To achieve optimal health for all, NCCDPHP's work on the social determinants of health extends beyond the scope of traditional public health practice to include collaboration in education, housing, transportation, justice, labor, and other sectors. Using four approaches, the NCCDPHP supports the following activities to prevent and control disease:

- *Surveillance and applied research:* To measure and monitor trends in the burden of chronic disease and associated risk factors, the NCCDPHP supports several surveillance systems including, but not limited to, the Behavioral Risk Factor Surveillance System (BRFSS), Youth Tobacco Survey, Pregnancy Risk Assessment Monitoring System, and National Program of Cancer Registries. The NCCDPHP has a network of more than 30 academic centers that conduct research to address health problems identified by communities.
- *Promotion of policy, environmental, and system changes at the state and community levels:* As an example, for the past four decades, the Office on Smoking and Health has reviewed research and provided 30 scientific reports on health and the use of tobacco.
- *Health communications:* This approach includes paid advertising, media advocacy, public relations, and health promotion activities.
- *Healthcare system linkages:* The NCCDPHP works with the healthcare system through provision of services such as mammography

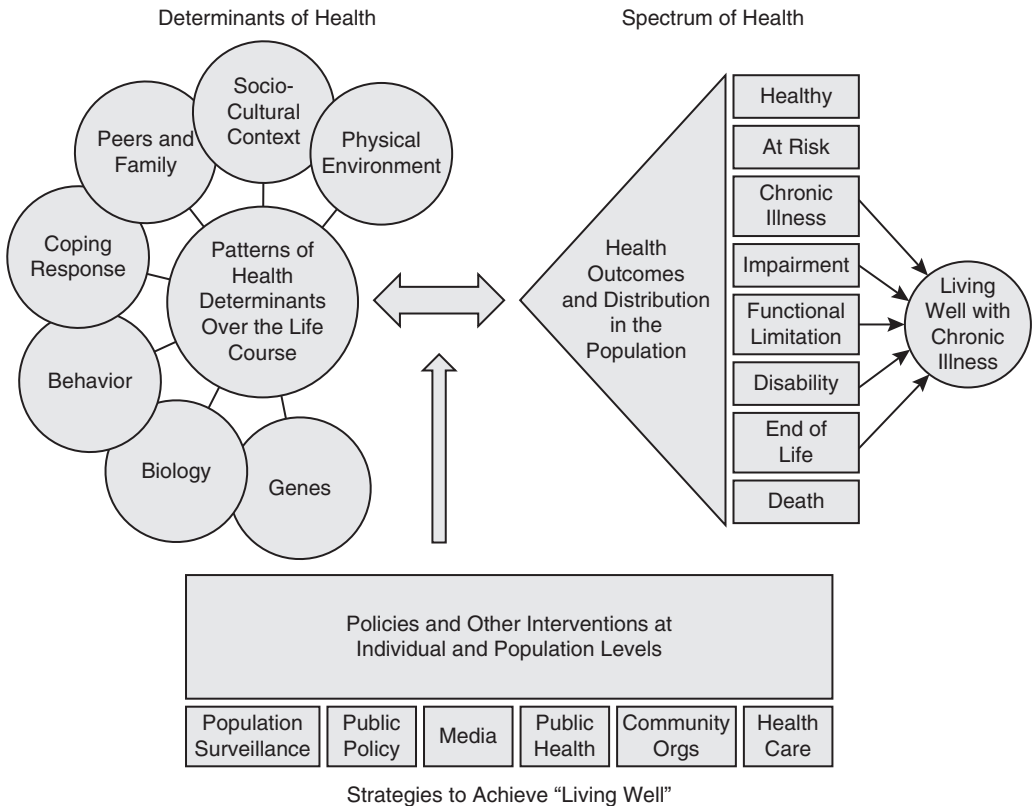
and tobacco cessation counseling for underserved populations; it is also working on issues of access to care, planned care, self-management, patient navigation, and quality prevention services (CDC, 2015).

## Health and Medicine Division (formerly the Institute of Medicine)

*Living Well with Chronic Illness: A Call for Public Health Action* (2012) is a report from a committee of the IOM. The IOM contends that better efforts are needed to maintain or enhance quality of life for individuals and families living with chronic illness. The report describes nine exemplar diseases, health conditions, and impairments that have significant implications for the health and economy of the U.S.; impact quality of life and functional status; cut across many illnesses and complications, and/or increase risks for multiple chronic conditions; and impact the community, families, and caregivers of those with chronic disease (p. xvi). These conditions are arthritis, cancer survivorship, chronic pain, dementia, depression, type 2 diabetes, post-traumatic disabling conditions, schizophrenia, and vision and hearing loss. The IOM report notes that identifying these conditions does not mean that they are more burdensome or important than others, but rather that each illustrates a key functionality or part of a chronic condition. In fact, the authors of this report were advised to not focus on the common high-mortality diseases, but to consider conditions that have the potential to cause or actually do cause functional limitations and/or disabilities (p. 23).

The IOM considers chronic disease to be a public health problem as well as a clinical problem. Using that lens to view the problem means that a population health perspective is necessary to develop interventions and policies. Thus, the best framework to approach chronic disease is an integrated one. The IOM committee adopted the concept of "living well," originally proposed by Lorig and colleagues





**FIGURE 1-1** Integrated framework for living well with chronic illness.

Reproduced from Institute of Medicine. (2012). *Living well with chronic illness: A call for public health action*. Washington, DC: National Academies Press, p. 32.

(2006), to reflect the best achievable state of health that encompasses all dimensions of physical, mental, and social well-being (p. 32). The concept of living well, integrated within a broader population health framework, is intended to promote a more holistic perspective beyond the traditional focus on other goals such as primary prevention or expansion of life expectancy (p. 33). **FIGURE 1-1** depicts the framework proposed by the IOM.

The IOM committee's 17 recommendations addressed 7 questions from the statement of task:

- Which chronic diseases should be the focus of public health efforts to reduce disability and improve functioning and quality of life (p. 10)?
- Which populations need to be the focus of interventions to reduce the consequences of chronic disease, including the burden of disability, loss of productivity and functioning, healthcare costs, and reduced quality of life (p. 11)?
- What is the role of primary prevention (for those at highest risk), secondary prevention, and tertiary prevention of chronic disease in reducing or minimizing life impacts (p. 12)?
- Which consequences of chronic diseases are most important to the nation's health and economic well-being (p. 13)?
- Which policy priorities could advance efforts to improve life impacts of chronic disease (p. 14)?
- Which population-based interventions can help achieve outcomes that maintain

or improve quality of life, functioning, and disability (p. 15)?

- What is the evidence on the effectiveness of interventions on these outcomes?
  - To what extent do the interventions that address these outcomes also affect clinical outcomes?
  - To what extent can policy, environmental, and systems change achieve these outcomes?
- How can public health surveillance be used to inform public policy decisions to minimize adverse life impacts (p. 18)?

A number of the recommendations involve the current and future work of the CDC. Many of the recommendations focus on research that needs to be completed to recognize if any of our current models of care for persons with chronic illness make a difference in quality of life. The recommendations are without priority order or measured ranking, as all are thought to be important strategies and steps to undergird public health action to enable individuals to live well with chronic illness (p. 8). All recommendations, as noted earlier, are based on a public health model.

## World Health Organization

The WHO plan for prevention and control of noncommunicable diseases (NCDs) is titled the *WHO global action plan for prevention and control of NCDs 2013–2020*. It provides a road map and a menu of policy options for all WHO member states and other stakeholders, as they take coordinated and coherent action, at all levels, local to global, to attain the nine voluntary global targets. As an example, one of the targets is a 25% relative reduction in premature mortality rate from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases by 2025.

WHO's vision for the plan is to have a world free of the avoidable burden of NCDs, with a goal of reducing the preventable and avoidable burden of morbidity, death, and disability due to noncommunicable diseases by means of multisectoral collaboration and cooperation at regional, national, and global levels. The ideal is

for populations to reach the highest attainable standards of health and productivity at every age and for those diseases to no longer be a barrier to well-being or socioeconomic development.

The focus of this action plan includes four NCDs—cardiovascular diseases, cancer, chronic respiratory diseases, and diabetes (which collectively make the largest contribution to morbidity and mortality associated with NCDs)—and four shared behavioral risk factors—tobacco use, unhealthy diet, physical inactivity, and harmful use of alcohol. WHO recognizes that the conditions in which people live and work and their lifestyles influence their health and quality of life (WHO, 2013b).

The overarching principles and approaches advocated within the plan include the following: (1) a human rights approach; (2) an equity-based approach; (3) national action, international cooperation, and solidarity; (4) multisectoral action; (5) life-course approach; (6) empowerment of people and communities; (7) evidence-based strategies; (8) universal health coverage; and (9) management of real, perceived, and potential conflicts of interest (WHO, 2013b).

## ► Summary

The United States touts itself as having the most sophisticated and technologically advanced health care in the world. Such health care should produce optimal patient outcomes rivaled by none. With U.S. healthcare expenditures now accounting for 17.8% of the country's GDP, it is clear that sophisticated health care comes at a price. Currently the United States spends \$9,990 per capita to provide this care—yet outcomes are not optimal and quality care and access to care lag far behind those found in other wealthy nations. When compared with the OECD countries, the United States ranks below the median on most core measures while having the most expensive health care in the world. Life expectancy for U.S. citizens now ranks in the bottom quartile of the 34 countries in the OECD. How can that be explained? What can be done to improve access to care and quality of care?

## Study Questions

1. Identify the influences that have led to the increased incidence of chronic disease in the United States and globally.
2. How can we better educate healthcare professionals to care for those with chronic disease? To care for older adults with chronic disease?
3. Compare and contrast chronic disease and chronic illness.
4. What actions can the United States take to decrease healthcare disparities?
5. Discuss the expanded role of RNs in chronic disease. What are the pros and cons of such action?

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