

# PART I

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## Impact of the Disease to the Individual and Family



## Chapter 1

# Chronicity

Pamala D. Larsen

Addressing the issues of chronic illness is a global challenge. In September 2011, for the first time, the United Nations discussed the topic of chronic disease as a principal theme at a plenary gathering (Institute of Medicine [IOM], 2012). The prevalence of chronic disease on a worldwide basis is similar to, if not greater than, it is in the United States. The World Health Organization (WHO) views chronic disease as a silent pandemic spreading to all parts of the world. Coronary heart disease, stroke, cancer, chronic obstructive pulmonary disease, diabetes mellitus type 2, neurodegenerative disease, and renal failure accounted for more than 62% of all deaths worldwide in 2011 (Harris, 2013). Twenty percent of chronic disease deaths occur in high-income countries, whereas the remaining 80% occur in low- and middle-income countries (WHO, 2013a).

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” (Harris, 2013, p. 1). These epidemiologic transitions are dynamic, wherein some diseases may disappear while others reoccur; 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 aging of the population, the real situation is much more complex. Epidemiological transitions reflect dynamic patterns of health and disease due to demographic, socioeconomic, technologic, cultural, environmental, and biologic changes (p. 8).

Chronic diseases are common and costly, but preventable. 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], 2009).

## Introduction

The most current prevalence data for U.S. chronic disease were collected in 2005, when it was estimated that 133 million individuals in the United States were living with at least one chronic disease (CDC, 2009; IOM, 2012; National Health Council, 2013), and that 7 of every 10 Americans who died each year—more than 1.7 million people—died of a chronic disease. Chronic disease accounts for one-third of the years of potential life lost before age 65. Statistics that quantify the costs from chronic disease are sobering:

- The direct and indirect costs of diabetes amounted to \$245 billion in 2012 (American

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Diabetes Association, 2013). These costs have increased 41% over the last 5 years.

- In 2011, the cost of heart disease totaled \$108.9 billion (CDC, 2014).
- In 2010 the total direct and indirect costs of cardiovascular disease and stroke in the United States were estimated to be \$314.4 billion (American Heart Association, 2014).
- The direct cost of cancer care amounted to \$124.7 billion in 2010 (National Cancer Institute, 2011).
- The medical costs of people with chronic disease account for more than 75% of the United States' \$2 trillion medical care costs each year (CDC, 2009).
- By 2030, the global economic burden of noncommunicable diseases is estimated to be \$47 trillion (Bloom et al., 2011).

In 2000, minorities represented 16.3% (5.7 million) of older American adults. By 2011, their number had risen to 8.5 million, and projections indicate that the minority older-adult population will increase to 20.2 million by 2030 (28% of the elderly) (Administration on Aging [AOA], 2012). How will the current system or a future system cope with this diverse group of seniors and their accompanying chronic conditions?

Multiple factors have combined to increase the number of individuals with chronic disease. Advances in the fields of public health, genetics, immunology, technology, and pharmacology have led to a significant decrease in mortality from acute disease. This medical success has contributed, in part, to the unprecedented growth of chronic illness by extending life expectancy and by facilitating earlier detection of disease in general. Living longer, however, leads to greater vulnerability to the occurrence of accidents and disease events that can become chronic in nature. The client who may have died from a myocardial infarction in the past now needs continuing health care for heart failure. The cancer survivor has healthcare needs related to the iatrogenic results of the life-saving treatment. The adolescent who is a quadriplegic because of an

accident may live a relatively long life, but needs a lifetime of preventive and maintenance care from the healthcare system. Children with cystic fibrosis have benefited from lung transplantation, but need care for the rest of their lives. As these examples suggest, many previously fatal conditions, injuries, and diseases have become chronic in nature.

### *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 the disease is important, but it is just as important to recognize the illness experience in providing holistic care.

*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.*

—Jenny

*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)*

Patient stories chronicle the illness experience; the illness experience is also nursing's domain. Thus, the focus of this book is on the chronic illness experience of individuals and families, and not specific disease processes. While chronic disease cannot be cured, nursing can make a difference in the illness experience with care instead of cure.

### *Acute Conditions Versus Chronic Conditions*

When an individual develops an acute disease, there is typically a sudden onset, with signs and symptoms related to the pathophysiology itself. Acute diseases end in a relatively short time, either with recovery and resumption of prior activities, or with death.

Chronic illness, by comparison, continues indefinitely. Although a welcome alternative to death in most, but not all, cases, the illness may be seen as a mixed blessing to the individual and the family. In addition, the illness often becomes the person's identity. For example, an individual having any kind of cancer, even in remission, may acquire the label of "that person with cancer." Chronic conditions take many forms, and there is no single onset pattern. A chronic disease can appear suddenly or through an insidious process, be associated with episodic flare-ups or exacerbations, or remain in remission with an absence of symptoms for long periods of time. Maintaining wellness or keeping symptoms in remission is a juggling act of balancing treatment regimens, maintaining quality of life, and having a normal life.

### *Defining Chronicity*

Defining chronicity is complex. Initially, the characteristics of chronic diseases were identified by the Commission on Chronic Illness as all impairments or deviations from normal that

included one or more of the following: permanency; residual disability; nonpathologic alteration; required rehabilitation; or a long period of supervision, observation, and care (Mayo, 1956). The extent of a chronic disease further complicates attempts in defining this term. 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 client'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, making them eligible to be defined as a chronic illness. Life-saving procedures create other problems. Of particular note are the chemotherapies and radiation therapy treatments for cancer. Studies have demonstrated that these life-saving treatments that may have occurred many years ago often lead to the development of a new cancer.

Chronic illness, by its very nature, is never completely cured. Biologically, the human body wears out unevenly. Older adults need a progressively wider variety of specialized services for increasingly complicated conditions. In the classic words of Emanuel (1982), "Life is the accumulation of chronic illness beneath the load of which we eventually succumb" (p. 502).

Although definitions of chronic disease are important, from a nursing perspective we are far more interested in how the disease psychosocially affects the client and family. What is the illness experience of the client and family? Perhaps the onus of defining chronic illness—and similarly, quality of life—should be placed on the client, as only the client 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*

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*behaviors. Their values are influenced by demographic, socioeconomic, technological, cultural, and environmental variables. The lived experience is “known” only to the individual and family.*

## 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: 2012*, the older population (65 years and older) numbered 41.4 million in 2011, an increase of 18% since 2000. By 2030, it is projected there will be 72.1 million adults in the United States who are older than 65 years, and by 2040 the population will reach 79.7 million (AOA, 2012).

Medicare Part A beneficiaries had more chronic conditions, on average, in 2010 than in 2008 (Erdem, 2014). The percentage increase in the average number of chronic conditions was larger for dual-eligible beneficiaries (2.8%) than for non-dual-eligible beneficiaries (1.2%). During the time period of 2008–2010, the prevalence of some chronic conditions decreased, such as congestive heart failure, ischemic heart disease, and stroke. The deterioration of average health, therefore, was due to other chronic conditions: chronic kidney disease, depression, diabetes, osteoporosis, and rheumatoid arthritis/osteoarthritis.

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 out of every three older Americans

having multiple chronic conditions (MCC), 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)

With MCC, these older adults will access—if their socioeconomic status permits—an acute care system. How will the needs of these aging adults influence our healthcare delivery system?

### *Healthy People 2020*

*Healthy People 2020* provides science-based, 10-year national objectives for improving the health of all Americans (<http://www.healthypeople.gov>). With 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	Human immunodeficiency virus (HIV) infection
Adolescent health	Immunization and infectious diseases
Arthritis, osteoporosis, and chronic back conditions	Injury and violence prevention
Blood disorders and blood safety	Lesbian, gay, bisexual, and transgender health
Cancer	Maternal, infant, and child health
Chronic kidney disease	Medical product safety
Dementias, including Alzheimer's disease	Mental health and mental disorders
Diabetes	Nutrition and weight status
Disability and health	Occupational safety and health
Early and middle childhood	Older adults
Educational and community-based programs	Oral health
Environmental health	Physical activity
Family planning	Preparedness
Food safety	Public health infrastructure
Genomics	Respiratory diseases
Global health	Sexually transmitted diseases
Health communication and health information technology	Sleep health
Healthcare-associated infections	Social determinants of health
Health-related quality of life and well-being	Substance abuse
Hearing and other sensory or communication disorders	Tobacco use
Heart disease and stroke	Vision

Source: *Healthy People 2020*. Topics and objectives index. Retrieved from <http://healthypeople.gov/2020/topicsobjectives2020/default.aspx>.



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*National Healthcare Quality Report*

The National Healthcare Quality Report (U.S. Department of Health and Human Services [USDHHS], 2013) is an indicator of how we, as a country, are doing with quality of care and health disparities. The statistics on quality and access to care are vitally important to individuals across this country. 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. Prevention is the key to many chronic conditions, but if there is little quality care and poor access, health outcomes tend to be poor.

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 when assessing the healthcare system. The 2013 annual report addresses three questions:

- What is the status of healthcare quality and disparities in the United States?
- How have healthcare quality and disparities changed over time?
- Where is the greatest need to improve healthcare quality and reduce disparities? (USDHHS, 2013, p. 1).

Three themes have emerged from this report that emphasize the need to accelerate progress if this country is to achieve higher quality and more equitable health care in the near future:

- Healthcare quality and access are suboptimal in the United States, especially for minority and low-income groups.
- Overall quality is improving, access is getting worse, and disparities are not changing
- Urgent attention is warranted to ensure continued improvements in the following areas:
  - Quality of diabetes care, maternal and child health care, and adverse events
  - Disparities in cancer care
  - Quality of care among states in the South (USDHHS, 2013, p. 2)

Compared with the 2009 report, whose findings were presented in the previous edition of this text, there has been little change in the themes noted over the 4-year period. What follows are selected examples of the health disparities present in the United States today and the limited access that minority or disadvantaged people have to health care.

- Disparities in quality of care are common.
  - Blacks received worse care than whites, and Hispanics received worse care than non-Hispanic whites for approximately 40% of quality measures.
  - Poor and low-income people received worse care than high-income people for 60% of quality measures; middle-income people received worse care for more than half of the measures (USDHHS, 2013, p. 3).
- Disparities in access are also common, especially among American Indians, Alaska Natives, Hispanics, and poor people.
  - Hispanics had worse access to care than non-Hispanic whites for about 70% of measures.
  - Poor people had worse access to care than high-income people for all measures, low-income people had worse access to care for more than 80% of measures,



and middle-income people had worse access to care for 70% of measures (USDHHS, 2013, p. 4).

The National Healthcare Quality Report is plagued by the same problem every year—namely, the data on underserved populations are often incomplete. Some data sources do not collect information to identify specific groups; other sources collect the information, but the numbers in each group are too small for reliable estimates (USDHHS, 2013, p. 9). Obtaining reliable data has been included as a priority in the *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* (National Partnership for Action to End Health Disparities, 2011).

The NHQR has identified some issues that demonstrate *worsening quality of care*, which may lead to chronic physical or mental conditions:

- Children ages 19–35 months who receive three or more doses of *Haemophilus influenzae* type B vaccine
- Maternal deaths per 100,000 live births
- Adults age 40 and older with diagnosed diabetes who had their feet checked for sores or irritation in the calendar year
- Postoperative pulmonary embolism or deep vein thrombosis per 1,000 surgical admissions, age 18 and older
- Admissions for asthma per 100,000 population, age 65 and older
- Adults age 40 and older with diagnosed diabetes who received two or more hemoglobin A<sub>1c</sub> measurements in the calendar year
- Suicide deaths per 100,000 population
- Women ages 21–65 who received a Pap smear in the last 3 years
- Admissions with Stage III or IV pressure ulcers per 1,000 medical and surgical admissions of length of stay of 5 or more days
- Admissions of patients with diabetes with short-term complications per 100,000

population, age 18 and older (USDHHS, 2013, p. 13)

Finally, the NHQR reports *disparities that are worsening over time*:

- Advanced-stage invasive breast cancer incidence per 100,000 women age 40 and older
- Maternal deaths per 100,000 live births
- Adjusted incidence of end-stage renal disease due to diabetes per 1 million population
- Hospice patients who received the right amount of help for feelings of anxiety or sadness
- Adults ages 18–64 at high risk (e.g., because of chronic obstructive pulmonary disease [COPD]) who have ever received pneumococcal vaccination
- Hospital patients with heart failure and left ventricular systolic dysfunction who were prescribed an angiotensin-converting enzyme (ACE) inhibitor or angiotensin-receptor blocker (ARB) at discharge
- Adults age 50 and older who ever received a colonoscopy, sigmoidoscopy, or proctoscopy
- Home healthcare patients who have less shortness of breath
- Adults age 40 and older with a diagnosis of diabetes who received more than 2 hemoglobin A<sub>1c</sub> measurements in the calendar year
- Hospital patients with heart attack who received fibrinolytic medication within 30 minutes of arrival (USDHHS, 2013, p. 14)

### *The Healthcare Consumer*

The influx of baby boomers into organizations such as AARP has distinctly affected the activities of that organization and other similar types of organizations. In addition, the new 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

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treatment options. They question their health-care 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 the advances in information technology (IT) (Frist, 2014). Neither of these were significant drivers of health care even 3 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, including living conditions, access to food, and education status (Frist, 2014). The number of individuals with chronic disease is climbing, but to avert those conditions for millions of others who are at risk, society must make healthy choices easy for individuals to embrace in their daily lives.

### *Financial Impact*

Total U.S. healthcare spending increased by 3.7% to \$2.8 trillion or \$8,915 per person in 2012 as compared with data from 2011 (Martin, Hartman, Whittle, Catlin & National Health Expenditure Accounts Team, 2014). Growth has remained fairly stable since 2009, primarily due to the impact of the economic recession (p. 67).

In 2012, the U.S. gross domestic product (GDP) grew almost 1 percentage point faster than the country’s health spending did. As a result, the share of the U.S. economy devoted to health care in 2012 was 17.3% as compared

with 17.2% in 2011, and considerably smaller than the high of 17.6% of the GDP in 2009. Martin and colleagues (2014) note several important findings:

- Personal healthcare spending (healthcare goods and services) accounted for 85% of the overall national health spending, increasing 3.9% in 2012. The recession contributed to slower growth in private health insurance spending and out-of-pocket spending by consumers.
- The increase in personal healthcare spending in 2012 was influenced primarily by hospital services, for which spending increased 4.9% in 2012 as compared with 3.5% in 2011.
- Spending for physician and clinical services increased 4.6% in 2012, up from a 4.1% increase in 2011. The faster growth in these services was driven primarily by increases in the volume and intensity of services provided.
- Partially offsetting the increased growth in hospital care and clinician services was slower growth in spending for prescription drugs and nursing home care. The rate of growth for nursing home spending slowed to 1.6% as compared with 4.3% in 2011; this drop is partly attributable to Medicare’s reduced payments for skilled nursing facilities that sought to adjust for the large increase in payments that occurred in 2011. Total retail prescription drug spending growth slowed in 2012, increasing by only 0.4%, compared with 2.5% in 2011. This reduced growth rate was driven largely by a decrease in the overall prices paid for retail prescription drugs as numerous brand-name drugs lost their patent protection (e.g., Lipitor, Plavix, and Singulair) (Martin et al., 2014, pp. 67–72).

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 assist clients in living longer lives, these costs will only increase.

Recent data from the National Health Interview Survey (NHIS) from 2012 found that one in four families experienced a financial burden in paying for medical care. One in 10 persons in a family was unable to pay anything toward their health care (Cohen & Kirzinger, 2014). Additionally, one in three families with children experienced 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. In 2011, the annual health expenditure per capita (incorporating both public and private expenditures) for an individual in the United States was \$8,508 (the 2012 amount was \$8,915, as mentioned earlier). This number is significantly higher than that for Norway (\$5,669), ranked number 2, and Switzerland (\$5,643), ranked number 3 (OECD, 2013). Americans spent more than twice as much on health care as relatively rich countries such as France and Sweden. In fact, the United States spent more than two-and-one-half times the amount that the average OECD country spent on health care, which was \$3,339 (adjusted for purchasing power parity).

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 8.7), 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 1½ years less than the OECD average of 80.1 years. Switzerland, Japan, Italy, and Spain are the OECD countries with the highest life expectancies, exceeding 82 years (OECD, 2013). Certainly one health risk factor—obesity—has affected any increase in life expectancy. The obesity rate among adults in the United States was 36.5% in 2011, up from 15% in 1978. 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. This rate in the United States decreased from 33.5% in 1980 to 14.8% in 2011. Only Sweden and Iceland have lower rates of smoking.

## Interventions

Chronic disease is an issue that is all encompassing, such that interventions from many sources are needed to make a difference. Professional education, evidence-based practice, and legislation affect any potential interventions. Lastly, paradigms from the Centers for Disease Control and Prevention, the Institute of Medicine, and the World Health Organization address chronic disease and ways to mitigate its impact.

### *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.

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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 (Table 1-2). At first glance, the competencies might not seem unique. However, 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 that criticized physicians for not conducting rigorous reviews of evidence to ensure that they were making appropriate treatment decisions. Cochrane was

## Table 1-2 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

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a proponent of randomized clinical trials, and in his exemplar case noted that thousands of low-birth-weight premature infants died needlessly. At the same time there were several randomized controlled trials (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 this therapy was effective in halting premature labor and thus reducing infant deaths due to prematurity. Cochrane died in 1988, but as a result of his influence and call for systematic review of the literature, the Cochrane Collaboration was launched 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 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. health-care 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). Some components of the law address individuals with chronic illness:

- A Patient's Bill of Rights was established.
- High-risk insurance pools were created to make insurance available to individuals with preexisting health conditions until healthcare coverage exchanges are operational in 2014.
- Insurers are no longer able to exclude children with preexisting conditions from being covered under their parents' insurance.
- Insurers are not able to rescind policies to avoid paying medical bills when a person becomes ill.
- Lifetime limits on coverage are prohibited.
- Children are able to stay covered under their parents' insurance plan until age 26.
- Funding for scholarships and loan repayments for primary care practitioners working with underserved populations was expanded.
- Insurers will no longer be able to refuse to sell or renew policies because of an individual's health status, and will no longer be able to exclude coverage for an individual of any age because of a preexisting condition (effective 2014).
- Insurers can no longer charge higher rates because of an individual's health status or gender (effective 2014).
- Health plans will be prohibited from imposing any annual limits on coverage (effective 2014).
- Health plans will no longer be able to charge copayments and deductibles for recommended preventive care (effective 2014).
- Health insurance exchanges will open in each state, allowing individuals and small employers to shop for health insurance policies (effective 2014).
- Tax credits are available to those whose income is above Medicaid eligibility and



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below 400% of the poverty level and do not receive acceptable coverage. Additionally, Medicaid eligibility will increase to 133% of the poverty level for all non-elderly individuals (“The Affordable Care Act: One Year Later,” 2011).

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 website. In going forward, one of the challenges of the ACA will be ensuring that its benefits become apparent quickly and dramatically enough to offset the problems (Jost, 2014, p. 10). The ACA does address the real problem of millions of uninsured Americans, and if it succeeds, it will be considered successful; however, it is still too early to know the full impact of the ACA.

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

According to the CDC (2009), the key chronic diseases in the United States are the following:

- Heart disease and stroke are the first and third leading causes of death, respectively, accounting for more than 30% of all U.S. deaths each year.
- Cancer, the second leading cause of death, claims more than 500,000 lives each year.
- Diabetes is the leading cause of kidney failure, nontraumatic lower-extremity amputations, and new cases of blindness each year among U.S. adults aged 20–74 years.

- Arthritis, the most common cause of disability, limits activity for 19 million U.S. adults.
- Obesity has become a major health concern for people of all ages. One in every 3 adults and nearly 1 in every 5 young people aged 6–19 are obese.

The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) is at the forefront of the nation’s efforts to promote health and well-being through prevention and control of chronic disease. The NCCDPHP provides leadership to achieve three primary goals:

- Prevent, delay, detect, and control chronic diseases
- Contribute to chronic disease research and apply that research to implement practice and effective intervention strategies
- Achieve equity in health by eliminating racial and ethnic disparities and achieving optimal health for all Americans (CDC, 2009)

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. The NCCDPHP supports the following activities to prevent and control diseases:

- *Surveillance and applied research:* Measuring and monitoring 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 systems 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:* Includes paid advertising, media advocacy, public relations, and health promotion activities.
- *Healthcare system linkages:* Include working with the healthcare system through provision of services such as mammography and tobacco cessation counseling for underserved populations; and working on issues of access to care, planned care, self-management, patient navigation, and quality prevention services (CDC, 2009).

### *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 need to be made to maintain or enhance quality of life for individuals and families living with chronic illness. The report (in book form) describes nine exemplar diseases, health conditions, and impairments that have significant implications for the United States' health and economy; 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 in this way 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).

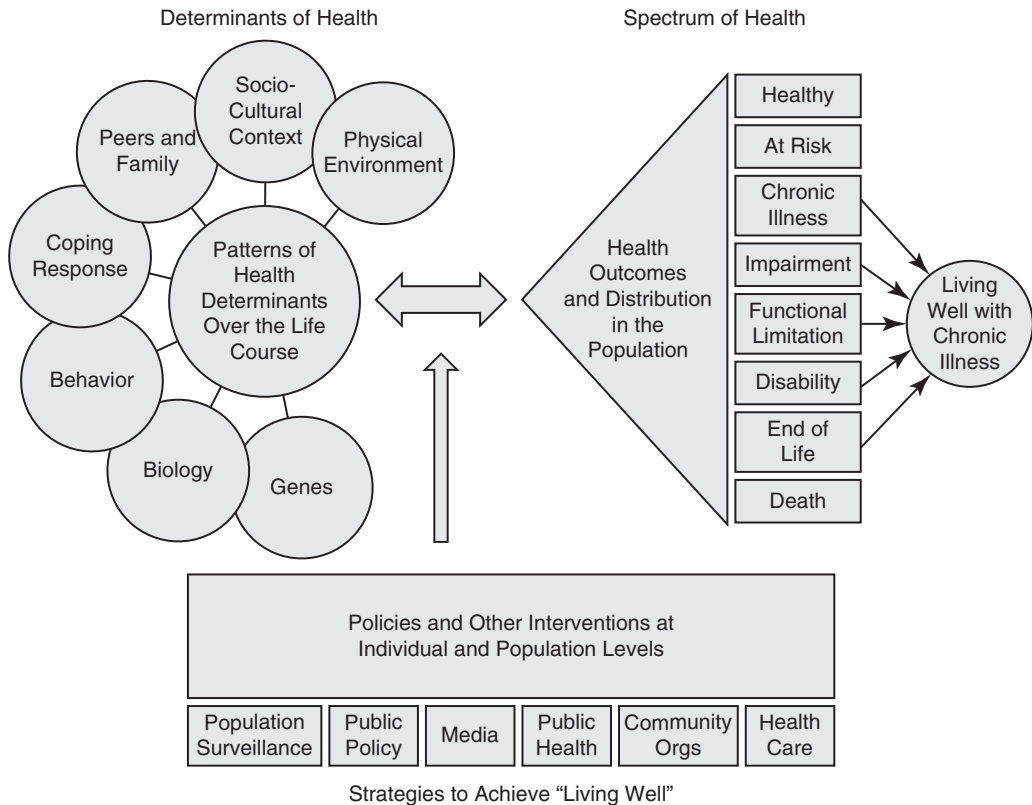
The IOM considers chronic disease to be a public health problem as well as a clinical problem. Using that lens to view the problem means that a population health perspective is necessary to develop interventions and policies. Thus, the best framework to approach chronic disease is an integrated one. The IOM committee adopted the concept of "living well," as proposed by Lorig and colleagues (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 work of this IOM committee is vast and its findings have been compiled in a book with more than 300 pages. The IOM committee's 17 recommendations addressed 7 questions from the statement of task. Questions included:

- 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,



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

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

- 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?
- 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 (p. 15)?
- 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 those 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*

WHO has updated its plan for prevention and control of noncommunicable diseases (NCD), the term the organization uses for chronic diseases. The plan, titled the *WHO Global Action Plan for Prevention and Control of NCDs 2013–2020*, 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. For example, one of those targets is a 25% relative reduction in premature mortality 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 noncommunicable diseases, with a goal of reducing the preventable and avoidable burden of morbidity, mortality, and disability due to noncommunicable diseases by means of multisectoral collaboration and cooperation at national, regional, 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 due to 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. health-care expenditures now accounting for 17.2% of the country's GDP, it is clear that sophisticated health care comes at a price. Currently the United States spends \$8,915 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 industrialized 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 30 countries in the OECD. How can we explain that? What can be done to improve care?

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## STUDY QUESTIONS

1. Summarize the epidemiology of chronic disease in the United States and globally today.
2. Which factors and influences have led to the increased incidence of chronic disease in the United States and globally?
3. How can we better educate healthcare professionals to care for those with chronic disease? To care for older adults with chronic disease?
4. Compare and contrast chronic disease and chronic illness.
5. Which actions should the United States take to decrease healthcare disparities?

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