

# PART I

## **Impact of the Disease**



## CHAPTER 1

# Chronicity

*Pamala D. Larsen*

The prevalence of chronic disease worldwide is similar if not greater than it is in the United States. Chronic diseases are the leading cause of death in the world, accounting for 60% of all deaths worldwide (World Health Organization [WHO], 2011). Twenty percent of chronic disease deaths occur in high-income countries, whereas the remaining 80% occur in low- and middle-income countries, where most of the world's population resides (WHO, 2011).

There is a wide variety of conditions that are considered chronic, and each condition needs a diverse array of services to care for affected individuals. For example, consider clients with Alzheimer's disease, cerebral palsy, heart disease, acquired immunodeficiency syndrome (AIDS), or spinal cord injury; each of these clients has unique physical needs, and each needs different services from a healthcare system that is attuned to delivering acute care.

The first baby boomers turned 65 in 2011, and this event has focused increased attention on the capabilities of the healthcare system. The baby boomer generation, in particular, has been vocal about the inability of the healthcare system to meet current needs, let alone future needs.

## INTRODUCTION

In 2005 it was estimated that there were 133 million individuals living with at least one chronic disease (Centers for Disease Control and Prevention [CDC], 2010a), and that 7 of every 10 Americans who die each year—or more than 1.7 million people—die of a chronic disease. Chronic disease accounts for one-third of the years of potential life lost before age 65. The data that have quantified the costs from chronic disease are quite sobering as well:

- The direct and indirect costs of diabetes were \$174 billion in 2007 (American Diabetes Association, 2011).
- In 2010, the cost of heart disease and stroke was \$316.4 billion (CDC, 2010b).
- The direct cost of cancer care in 2010 was \$124 billion (National Cancer Institute, 2011).
- The medical costs of people with chronic disease account for more than 75% of the nation's \$2 trillion medical care costs each year (CDC, 2008).

These facts 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, the costs will only increase.

The influx of baby boomers into organizations such as AARP has distinctly flavored the activities of that and other similar types of organizations. In addition, this new group of seniors is the most ethnically and racially diverse of any previous generation. This well educated, consumer-driven generation wants to be knowledgeable about their conditions and all treatment options. They question their healthcare providers and do not necessarily accept their healthcare advice and treatment options.

In 2000, minorities represented 16% of older American adults. By 2020 that percentage will increase to 24% (Administration on Aging [AOA], 2010). Unfortunately, the healthcare disparities that we have seen in the past regarding ethnic and racial groups are not decreasing, but rather increasing. Three key themes emerged from the 2009 National Health Disparities Report: 1) disparities are common and lack of health insurance is an important contributor; 2) many disparities are not decreasing; and 3) some disparities merit particular attention, especially care for cancer, heart failure, and pneumonia (Agency for Healthcare Research and Quality [AHRQ], 2010a). How will the current system or a future system cope with this diverse group of seniors and their accompanying chronic conditions?

Multiple factors have produced the increasing number of individuals with chronic disease. Developments in the fields of public health, genetics, immunology, technology, and pharmacology have led to a significant decrease in mortality from acute disease. Medical success has contributed, in part, to the unprecedented growth of chronic illness by extending life expectancy

and by 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 earlier years now needs continuing health care for heart failure. The cancer survivor has healthcare needs related to the iatrogenic results of life-saving treatment. The adolescent, who is a quadriplegic because of an accident, may live a relatively long life with our current rehabilitation efforts, but needs continuous 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. Therefore, 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 the condition, such as an alteration in structure and function. Illness, on the other hand, is the human experience of symptoms and suffering, and refers to how the disease is perceived, lived with, and responded to by individuals, their families, and their healthcare providers. Although it is important to recognize the pathophysiological process of a chronic disease, understanding the illness experience is essential to providing holistic care.

I put my elbows on my knees and let my forehead sink into my palms. I'm tired. Not just tired . . . weary. My husband's catheter went AWOL at one in the morning, and we've spent the rest of the night in the ER (How many nights does that make now?)

How many hours?) Noise and cold and too-bright lights and too-bright student doctors. Repeating Bruce's history, over and over. (Harleman, 2008, p. 74)

Today is the 19th day in a row that my husband has seen a healthcare provider, and actually a few of those times, he's seen 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 out-patient, a mishap with the jejunostomy tube . . . 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, wife of a 63-year-old cancer patient*

These patient stories chronicle part of the illness experience. The illness experience is nursing's domain. Thus, the focus of this book is on the illness experience of individuals and families, and not specific disease processes. While nursing cannot cure chronic disease, nursing can make a difference in the illness experience.

## 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 disease process itself. Acute diseases end in a relatively short time, either with recovery and resumption of prior activities, or with death.

Chronic illness, on the other hand, continues indefinitely. Although a welcome alternative to death in most, but not all cases, the illness is often seen as a mixed blessing to the individual and to society at large. In addition, the illness

often becomes the person's identity. For example, an individual having any kind of cancer, even in remission, acquires the label of "that person with cancer" (see Stigma, Chapter 3). Chronic conditions take many forms, and there is no single onset pattern. A chronic disease can appear suddenly or through an insidious process, have episodic flare-ups or exacerbations, or remain in remission with an absence of symptoms for long periods. Maintaining wellness or keeping symptoms in remission is a juggling act of balancing treatment regimens while focusing on quality of life.

## Defining Chronicity

Defining chronicity is complex. Many individuals have attempted to present an all encompassing definition of chronic illness. 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 the 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. Take, for example, the changes in lifestyle required of clients receiving

hemodialysis for end-stage renal disease (ESRD). Life-saving procedures can create other problems. For instance, abdominal radiation that arrested metastatic colon cancer when an individual was 30 years of age contributes to a malabsorption problem years later. Chemotherapy or radiation given to a client for an initial bout with cancer may be an influencing factor in the development of leukemia years later.

Chronic illness, by its very nature, is never completely cured. Biologically the human body wears out unevenly. Medical advances cause older adults to need a progressively wider variety of specialized services for increasingly complicated conditions. In the 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 illness is affecting the client and family. What is the illness experience of the client and family? Price (1996) suggests that the onus of defining chronic illness, and similarly, quality of life and comfort, should be that of the client’s, as only the client truly understands the illness. However, that aside, the following definition of chronic illness is offered: “Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability” (Curtin & Lubkin, 1995, pp. 6–7).

## IMPACT OF CHRONIC ILLNESS \_\_\_\_\_

This section addresses the influence of chronic illnesses and impact on society in general.

## 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. Julie Gerberding, former Director of the CDC, stated: “The aging of the U.S. population is one of the major public health challenges we face in the 21st century” (CDC & the Merck Company Foundation, 2007). In 2009 persons older than 65 years of age numbered 39.6 million and represented 12.9% of Americans (AOA, 2010). Since 1900, the percentage of older Americans has tripled. By 2030 there will be 72.1 million adults in the United States who are older than age 65 years, nearly double the current number and roughly 19% of the U.S. population (AOA, 2010). Increased life expectancy and medical advances have contributed to these demographic changes.

With age comes chronic disease. Six of the seven leading causes of death among older Americans are chronic diseases (Federal Interagency Forum on Aging-Related Statistics, 2010). Medicare data document that 83% of all of its beneficiaries have at least one chronic condition (Anderson, 2005). However, 23% of Medicare beneficiaries with five or more conditions account for 68% of the program’s funding (Anderson, 2005, p. 305).

A compounding factor in the physical health of older adults is the presence of depression, the occurrence of which is increasing in the older population. Himelhoch, Weller, Wu, Anderson, and Cooper (2004) analyzed data in a randomized sample of 1,238,895 Medicare recipients, with 60,382 of those clients meeting the criteria for a depressive syndrome. For each of eight chronic medical conditions, Medicare beneficiaries with a depressive syndrome were at least

twice as likely to use emergency department services and medical inpatient hospital services as those without depression (Himelhoch et al., 2004, p. 512).

As people age, it is clear they will have more chronic conditions and will access, if their socioeconomic status permits, an acute care system. How will the needs of these aging adults affect our healthcare delivery system? As mentioned previously, there is evidence of growing inequities in healthcare services that racial and ethnic minorities receive. Combine those inequities with being an older adult, and there is a significant population that will be without quality health care or perhaps any health care at all.

## The Healthcare Delivery System

The current healthcare system was largely designed and shaped in the 2 decades following World War II (Lynn & Adamson, 2003). In 1946 Congress passed Public Law 79-725, the Hospital Survey and Construction Act, sponsored by Senators Lister Hill and Harold Burton. The Hill-Burton Act was designed to provide federal grants to modernize hospitals that had become obsolete, owing to lack of capital investment throughout the Great Depression and World War II (1929–1945). The healthcare system was designed to provide acute, episodic, and curative care, and it was never intended to address the needs of individuals with chronic conditions. At the time, little, if any, thought was given to what “future patients” would look like. Generally, our present healthcare delivery system provides acute care effectively and efficiently. However, it is based on a component style of care in which each component or care setting of the system is reimbursed separately, that is, hospital, home care, physician visit.

Each component of the healthcare system views the client through its narrow window of care. No one entity, practice, institution, or agency is managing the entire disease, and certainly none is managing the illness experience of the client and family. No one entity is responsible for the overall care of the individual, only their own independent component of care. Typically this approach produces higher costs for the client.

The current healthcare delivery system is disease oriented. Clients fit within the “standards of care,” or the algorithm of a specific disease. With diagnosis-related groups (DRGs), payment is predetermined according to diagnosis as opposed to how many services are used. Think about an older adult in this system: Mr. Jones, with several comorbidities, enters the acute care institution. His admitting diagnosis is pneumonia, but now his diabetes is flaring up along with his hypertension, and his kidneys are not working as well as they should. A specialty physician is treating each of his conditions, but there is no coordinator of his care. He is taking multiple medications, and soon he becomes confused and incontinent. In addition, the focus of the acute care facility is the disease processes of this individual and not the illness experience of the patient and his elderly wife. What does our acute care system do with this older adult with multiple chronic health problems? How does our healthcare delivery system care for Mr. Jones and the multitude of others like him on the horizon?

## Healthy People 2020

*Healthy People 2020* provides science-based, 10-year national objectives for improving the health of all Americans (<http://www.healthy-people.gov>). For 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 to:

- 1) Identify nationwide health-improvement priorities.
- 2) Increase public awareness and understanding of the determinants of health, disease, and disability and the opportunities for progress.
- 3) Provide measurable objectives and goals that are applicable at the national, state, and local levels.
- 4) Engage multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge.
- 5) 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 and/or prevention of chronic disease.

## Quality of Care

In 1996 the Institute of Medicine (IOM) initiated a focus on assessing and improving the quality of care in the United States. A number of documents and books have evolved from that initiative. Perhaps the most known of those include *Crossing the Quality Chasm* (IOM, 2001)

and *To Err is Human* (IOM, 1999). The intent of these books and other documents was to increase awareness of quality and improve the health outcomes of individuals in the nation.

The quest for quality continues. Chassin and Loeb (2011) chronicle the quality improvement journey from Semmelweis, the Hungarian physician who discovered that childbed fever could be drastically cut by the use of hand washing standards in obstetric clinics, to the present day. These authors characterize healthcare quality and safety as “showing pockets of excellence on specific measures or in particular services at individual healthcare facilities” (p. 562). One example provided is that hospitals, on average, provide life-prolonging beta-blockers to heart attack patients 98% of the time (as cited in Chassin & Loeb, 2011). However, they contend that what is missing is *maintenance* of high levels of safety over time and across all healthcare services and settings.

Moreover, the available evidence suggests that the harmful error in health care may be increasing. As new devices, equipment, procedures, and drugs are added to our therapeutic arsenal, the complexity of delivering effective care increases. Complexity greatly increases the likelihood of error, especially in systems that perform at low levels of reliability. (Chassin & Loeb, 2011, p. 563)

This complex care causes medical errors. It has been documented that surgical procedures performed either on the wrong patient or at the wrong site on a patient still occur (Stahel et al., 2010). Medicare has termed these events as “never events”—serious, costly errors in patient care that should never happen (Centers for Medicare and Medicaid, 2008). Van Den Bos and colleagues (2011) estimate that the annual



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

Access to health services	HIV
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 July 24, 2011, from: <http://healthypeople.gov/2020/topicsobjectives2020/default.aspx>

\*New Topic Area

cost of medical errors that harm patients was \$17.1 billion in 2008 (p. 596).

Since 2003 the AHRQ with the Department of Health and Human Services (DHHS) has reported on quality measures. In the past, reports were based on 250 measures across 6 dimensions: effectiveness, patient safety, timeliness, patient centeredness, efficiency, and access to

care. For 2010 the AHRQ produced the National Healthcare Quality Report (NHQR) and the National Healthcare Disparities Report (NHDR), combining their summary of findings into one document in an effort to reinforce the need to consider simultaneously the quality of health care and disparities across populations when assessing the healthcare system. Four themes

from the 2010 NHQR and the 2010 NHDR emphasize the need to accelerate progress if the United States wants to achieve higher quality and more equitable health care in the near future:

- Healthcare quality and access are suboptimal, especially for minority and low-income groups.
- While quality is improving, access and disparities are not improving.
- Urgent attention is warranted to ensure improvements in quality and progress on reducing disparities with respect to certain services, geographic areas, and populations, including:
  - Cancer screening and management of diabetes
  - States in the central part of the country
  - Residents of inner city and rural areas
  - Disparities in preventive services and access to care
- Progress is uneven with respect to eight national priority areas:
  - Two are improving in quality: 1) palliative and end-of-life care, and 2) patient and family engagement
  - Three are lagging: 3) population health, 4) safety, and 5) access
  - Three require more data to assess: 6) care coordination, 7) overuse, and 8) health system infrastructure
  - All eight priority areas showed disparities related to race, ethnicity, and socioeconomic status. (AHRQ, 2010b)

Data across the country are contradictory. Although progress has been made in some areas, other areas have not seen any improvement. Data involving quality of care include the following:

- On average, patients received chronic disease management services three-quarters

of the time. Receipt of chronic disease management services varied widely, from 17% of dialysis patients being registered on a kidney transplant waiting list to 95% of hospice patients receiving the right amount of pain medication.

- On average, patients received preventive services two-thirds of the time, but there was a wide variation in receipt of those services. For instance, only 20% of high-risk adults ages 18–64 years received the pneumococcal vaccination, but 94% of children ages 19–35 months received 3 doses of polio vaccine.
- Access to care is limited. On average, Americans report barriers to care one-fifth of the time, ranging from 3% of people saying they were unable to get or had to delay getting prescription medications to 60% of people saying their usual provider did not have office hours on weekends or nights. (AHRQ, 2011).

Certainly, these data demonstrate that as a nation we have much work to do to improve the quality of care that our clients receive. More information is available in the AHRQ's annual reports, including a data breakdown by individual states. In addition, AHRQ includes *State Snapshots* on their website (<http://statesnapshots.ahrq.gov/>). This website documents the quality measures of each individual state.

## Health Disparities

The first National Healthcare Disparities Report (NHDR) sponsored by AHRQ was released in 2003. In 2011, the ninth report was issued. As mentioned in the section on quality, this year AHRQ integrated the findings from the 2010 NHDR and the 2010 NHQR to produce one

summary document. Disparities continue. The following are some examples from the summary (AHRQ, 2011):

- Blacks, American Indians, and Alaska Natives received worse care than whites for about 40% of the core measures.
- Hispanics/Latinos received worse care than non-Hispanic/Latino whites for about 60% of the core measures.
- Poor people received worse care than high-income people for about 80% of the core measures.
- Hispanics/Latinos had worse access to care than non-Hispanic/Latino whites for five of six core measures.
- Poor people had worse access to care than high-income people for all six core measures.
- Measures of acute treatment are improving; measures of preventive care and chronic disease management are lagging.

## Culture

Illness belief systems form a cultural milieu that defines one's attitudes about illness, both acute and chronic. Conceptions or misconceptions about the source of the disease, potential treatment, and possible outcomes are all influenced by these belief systems, and one's belief system is influenced by one's culture. Providing culturally competent care may be a daunting task; however, health care is not "one size fits all," and healthcare professionals must take the extra steps to ensure culturally competent care (see Culture and Cultural Components, Chapter 13).

Another way to view culture is to consider chronic illness as a culture. Although we often believe that each disease is different, there are multiple tasks that are similar, and illness experiences may look alike across diseases.

Strauss (1975) was among the first researchers to recognize the similar issues and tasks within the culture of chronic illness. Generally, the culture of chronic illness includes preventing and managing medical crises; managing a treatment regimen; controlling symptoms; the reordering of time; and social isolation. In 1984 Strauss and colleagues suggested that the basic strategy to cope with these issues was to normalize, not just to stay alive or keep symptoms under control, but to live as normally as possible (p. 79). Essentially, for a number of clients with chronic illness, a "new normal" must be created.

A number of years ago when teaching a chronic illness practicum to graduate students, this author developed a mini-ethnography project of the individuals who the students were caring for that semester. Students were caring for clients with a variety of diseases—HIV, liver disease, heart failure, rheumatoid arthritis, and breast cancer. Using grand tour questions that had been developed as a class, students interviewed their clients over the course of the semester. During the final weeks of seminar after the practicum was completed, students compiled the data from all of the clients and looked at the themes that emerged. The class was able to develop a clear concept of the culture of what it is like to have a chronic illness and to understand the vast number of similarities between individuals with a variety of chronic conditions.

## Social Influences

As a society we often stereotype individuals according to the color of their skin, their culture, and their ethnicity. Unfortunately, we behave in a similar fashion with individuals with chronic conditions and disabilities

(see Stigma, Chapter 3). To this day there are some individuals who avoid others who may be in a wheelchair, have visible signs of disease (burns, paralysis, amputations, etc.), have a diagnosis of AIDS, and so forth. While some efforts such as department store advertisements depicting individuals in wheelchairs may positively influence some behavior, as a nation, there is much progress to be made.

Publicly recognized individuals have stepped forward with stories about their own chronic conditions. The courage of these individuals to share their experiences and speak out for more comprehensive legislation to support those with chronic disease and increase research funding is admirable. Examples include Michael J. Fox and Muhammed Ali, with diagnoses of Parkinson's disease; Magic Johnson, with his diagnosis of HIV; and the late Christopher and Dana Reeve, as advocates for spinal cord injury research.

### Financial Impact

Healthcare spending in the United States grew only 4% in 2009—the lowest rate of increase in the 50-year history of the National Health Expenditure Accounts—to \$2.5 trillion, or \$8,086 per person (Martin, Lassman, Whittle, Catlin, & the National Health Expenditure Accounts Team, 2011). Researchers attribute several factors to this low rate of increase: “deceleration in private health insurance spending, a decline in spending on structures and equipment in the healthcare system, and slower growth in out-of-pocket spending” (p. 11).

Despite the slower growth, healthcare spending accounted for 17.6% of the gross domestic product (GDP) in 2009, up from 16.6% in 2008. This is the largest 1-year increase in the history of the national health accounts

(Martin et al., 2011). Martin and colleagues (2011) note several important findings:

- The growth rate of health spending outpaced the growth of the overall economy, which experienced its largest drop since 1938.
- The recession contributed to slower growth in private health insurance spending and out-of-pocket spending by consumers.
- Declining federal revenues and strong growth in federal health spending increased the health spending share of total federal revenue from 37.6% in 2008 to 54.2% in 2009.
- Faster growth in Medicaid spending, from 4.9% in 2008 to 9% in 2009, was driven by the addition of 3.5 million new enrollees.
- The number of uninsured people increased by 3.8 million, from 42.7 million in 2008 to 46.5 million in 2009.

Using Medical Expenditure Panel Survey (MEPS) data, five conditions have been identified as the most costly conditions in the noninstitutionalized population, and four of them are chronic conditions. The five conditions—heart disease, cancer, trauma-related disorders, mental disorders, and asthma—ranked highest in terms of direct medical spending in 1996 and again in 2006 (Soni, 2009). These data are based on expenditures (what is paid for healthcare services), and do not include any indirect costs. Heart disease had the largest medical expenditures in 2006 with \$78 billion, followed by trauma-related disorders at \$68.1 billion, cancer and mental disorders tied at \$57.5 billion, and asthma at \$51.3 billion (Soni, 2009). The largest increases in expenditures from 1996 to 2006 were for mental disorders and trauma-related disorders. The biggest increase in number of

people accounting for expenditures was for mental disorders, which nearly doubled in the 10-year period, while in terms of mean expenditures per person, costs were highest for cancer and heart disease in both 1996 and 2006 (Soni, 2009).

Compounding chronic disease is the issue of the uninsured. The long-term uninsured, versus those uninsured for short periods, is a significant population. MEPS data for 2002 to 2005 (the most current available) demonstrate the following in the population younger than 65 years of age: 17.4 million U.S. residents were uninsured for the entire 4-year period, and those reporting fair/poor health (11.2%) were the most likely to be uninsured for the entire 4-year period (Rhoades & Cohen, 2007). During the first half of 2009, 18.5% of the U.S. civilian noninstitutionalized population, numbering 55.6 million people, was uninsured. Among those under age 65, 55.3 million were uninsured. Young adults aged 19 to 24 and 25 to 29 were at the greatest risk of being uninsured. For the uninsured, 42.4% lived in the South, while 12.8% lived in the Northeast, 18.7% lived in the Midwest, and 26.2% lived in the West (Roberts & Rhoades, 2010). Among people under age 65, Hispanics/Latinos accounted for 29% of the uninsured U.S. civilian noninstitutionalized population even though they represented only 17% of the overall population of this age group (Roberts & Rhoades, 2010).

The Organization for Economic Cooperation and Development (OECD) annually tracks and reports on more than 1,200 health system measures across 30 industrialized countries. Since 1998, the Commonwealth Fund has sponsored an analysis of cross-national health systems based on OECD health data. According to data from 2006, the United States continues to differ

markedly from other countries (Anderson & Squires, 2010). The United States continues to outspend other countries in healthcare spending per capita at more than twice the median per capita expenditure of the 30 countries tracked by OECD. Compared with other countries, the United States has a low number of hospital beds and physicians per capita, and patients in the United States have fewer hospital and physician visits than most other countries. However, spending per hospital visit is the highest in the United States. Also, the United States ranks in the bottom quartile in life expectancy among these 30 countries and has seen the smallest improvement in this statistic over the past 20 years (Anderson & Squires, 2010). Life expectancy at birth in the United States was 77.8 years in 2006; however, ten countries had life expectancies at birth of more than 80 years. The United States' investment in technology has surely influenced health expenditure costs; however, Anderson and Squires contend that there is a gap between the investment in technically advanced equipment and procedures and what services are delivered in return. Either these health services are less effectively implemented or come at a higher price.

## INTERVENTIONS

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Chronic disease is an issue that is all encompassing, such that interventions from many sources will be needed to make a difference. What follows are examples of ways to decrease the impact of chronic disease.

### 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 those over the long haul with a chronic condition. The 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 those individuals with chronic conditions. The 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 the WHO (2005) were identified with 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: initial prevention of the chronic disease; and secondly, 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 (see **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 are in and out of the care system quickly, and there is less need for implementation of these concepts.

**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

Source: World Health Organization. (2005b). *Preparing a health care workforce for the 21st century: The challenge of chronic conditions* (p. 20). Geneva, Switzerland: WHO.

In 2007, the IOM charged an ad hoc committee with the task of determining the healthcare needs of an aging America, and, more importantly, developing recommendations to address those needs. On April 14, 2008, the IOM report, *Retooling for an Aging America: Building the Health Care Workforce*, was released to the public. This report suggests a three-pronged approach that includes the following: 1) enhance the geriatric competence of the entire workforce; 2) increase the recruitment and retention of geriatric specialists and caregivers; and 3) improve the way care is delivered (IOM, 2008).

The report states a well known fact: Little attention is paid to educating healthcare professionals about caring for older adults. The committee recommends that healthcare professionals be required to demonstrate their competence in caring for older adults as a criterion for licensure and certification. More stringent training standards would be implemented for direct-care providers by increasing existing federal training requirements and establishing state-based standards. And finally, because informal caregivers continue to play important roles in the care of older adults (with and without chronic illness), training opportunities should also be available for them (IOM, 2008).

Currently only a small percentage of the healthcare workforce specializes in caring for older adults. The IOM report recommends that financial incentives be provided to increase the number of geriatric specialists in every health profession. Incentives would include an increase in payments for clinical services, development of awards to increase the number of faculty in geriatrics, and the establishment of programs that would provide loan forgiveness, scholarships, and direct financial incentives for individuals to become specialists in geriatrics. For the direct-care workers in long-term care facilities that typically have high levels of turnover and job dissatisfaction, the recommendation is to improve job desirability, improve supervisory relationships, and provide opportunities for career growth. In addition, the report recommends that state Medicaid programs increase pay for direct-care workers and provide access to fringe benefits (IOM, 2008).

Lastly, models of care for older adults need to improve. The report envisions three key principles in improving care: 1) the healthcare needs

of older adults must be addressed comprehensively, 2) services need to be provided efficiently, and 3) older adults need to be encouraged to be active partners in their own care. Because no one model of care will be appropriate for all persons, the IOM recommends that Congress and public and private foundations significantly increase support for research and programs that promote development of new models of care (IOM, 2008).

## Chronic Disease Practitioner Competencies

From another point of view, the National Association of Chronic Disease Directors (NACDD) developed the document, “Competencies for Chronic Disease Practice.” The organization was founded in 1988 to link the directors of chronic disease programs in each state and U.S. territory. It created these competencies to assist state and local healthcare programs with developing competent workforces and effective programs. The NACDD document is based on domains, with individual competencies within each domain. Several of the domains address the WHO competencies (i.e., partnering, evidence-based interventions). Furthermore, the NACDD has developed an assessment tool for practitioners to gauge their level of proficiency in each of the seven domains. **Table 1-3** lists the competencies for chronic disease practitioners.

## Resources

### Centers for Disease Control and Prevention Programs

The CDC has provided both leadership and funding in developing state-based programs

**Table 1-3 National Association of Chronic Disease Directors: Competencies for Chronic Disease Practice**

<i>Domain 1—Build Support</i>	Chronic disease practitioners establish strong working relationships with stakeholders, including other programs, government agencies, and nongovernmental lay and professional groups, to build support for chronic disease prevention and control.
<i>Domain 2—Design and Evaluate Programs</i>	Chronic disease practitioners develop and implement evidence-based interventions and conduct evaluations to ensure ongoing feedback and program effectiveness.
<i>Domain 3—Influence Policies and Systems Change</i>	Chronic disease practitioners implement strategies to change the health-related policies of private organizations or governmental entities capable of affecting the health of targeted populations.
<i>Domain 4—Lead Strategically</i>	Chronic disease practitioners articulate health needs and strategic vision, serve as catalysts for change, and demonstrate program accomplishments to ensure continued funding and support within their scope of practice.
<i>Domain 5—Manage People</i>	Chronic disease practitioners oversee and support the optimal performance and growth of program staff as well as themselves.
<i>Domain 6—Manage Programs and Resources</i>	Chronic disease practitioners ensure the consistent administrative, financial, and staff support necessary to sustain successful implementation of planned activities and to build opportunities.
<i>Domain 7—Use Public Health Science</i>	Chronic disease practitioners gather, analyze, interpret, and disseminate data and research findings to define needs, identify priorities, and measure change.

Source: National Association of Chronic Disease Directors. *Competencies for chronic disease*. Retrieved July 24, 2011, from: <http://www.chronicdisease.org/professional-development/documents/workforce-dev/CompetenciesforChronicDiseasePractice.pdf>

nationwide. Programs have been developed to look at risk factors and prevention of disease and to examine ways to prevent complications and delay death resulting from chronic disease.

One example of the CDC's preventive work is with diabetes. The CDC's programs with diabetes encompass several components and include: promoting effective state programs, monitoring the burden and translating science, providing education and sharing expertise, supporting primary prevention, and targeting populations at

risk. What follows is a brief description of what each of these components provides.

- *Promoting effective state programs.* In 2007 the CDC provided funding for capacity building to 22 states, 8 current or former U.S. territories, and the District of Columbia for diabetes prevention and control programs. In addition, the CDC provided funding for basic implementation of programs in the other 28 states. The state programs identify



the disease burden in each state, develop and evaluate new prevention strategies, establish partnerships, increase awareness of prevention and control opportunities, and improve access to quality care. These projects continue in 2011 (CDC, 2011a).

- *Monitoring the burden and translating science.* The CDC analyzes data from several national sources, including the Behavioral Risk Factor Surveillance System. The translating of these data into quality practice is implemented with the assistance of other research partners, managed care organizations, and community health centers.
- *Providing education and sharing expertise.* Another component of the CDC's work is providing education. The National Diabetes Education Program (NDEP) is sponsored by both the CDC and the National Institutes of Health (NIH). The NDEP was launched in 1997 to improve diabetes management and reduce the morbidity and mortality from diabetes and its complications. The NDEP comprises more than 200 public and private partners. NDEP's major campaigns are based on landmark scientific studies on diabetes prevention and control, including the following:

- Diabetes Control and Complications Trial
- Epidemiology of Diabetes Interventions and Complications Study
- United Kingdom Prospective Diabetes Study
- Action to Control Cardiovascular Risk in Diabetes
- Veterans Affairs Diabetes Trial
- Diabetes Prevention Program

- Diabetes Prevention Program Outcomes Study
- Action for Health in Diabetes
- SEARCH for Diabetes in Youth (CDC, 2011b)

#### *REACH US*

The Racial and Ethnic Approaches to Community Health Across the United States (REACH US) is a national, multilevel program that serves as the cornerstone of the CDC's efforts to eliminate racial and ethnic disparities in health. Through REACH US, the CDC supports 40 grantee partners that establish community-based programs and culturally appropriate interventions to eliminate health disparities among African Americans, American Indians, Hispanics/Latinos, Asian Americans, Alaska Natives, and Pacific Islanders (CDC, 2011c). REACH US communities empower residents to 1) seek better health; 2) help change local health-care practices; and 3) mobilize communities to implement evidence-based public health programs that address their unique social, historical, economic, and cultural circumstances.

#### **Agency for Healthcare Research and Quality**

AHRQ sponsors a number of programs that are working to reduce or eliminate health disparities. These programs are described here because, as previously noted, 80% of U.S. healthcare dollars are spent on chronic disease. Therefore, health-care inequities largely involve chronic care.

AHRQ's goal of reducing/eliminating disparities is met through continued commitment to:

- Improving the quality of health care and healthcare services for patients and their

families, regardless of their race/ethnicity, socioeconomic status, and literacy level

- Continuing to improve the quality of data collected to address disparities among priority populations and subpopulations
- Promoting representation and inclusion of racial/ethnic minority populations in all health services research activities
- Monitoring and tracking changes in disparities by priority populations, subpopulations, and conditions
- Identifying and implementing effective strategies to reduce/eliminate disparities
- Partnering with communities to ensure that research activities are relevant to their populations and that the research findings are adopted and implemented effectively (AHRQ, 2009)

### **World Health Organization**

The WHO has updated its 2000 plan for the prevention and control of noncommunicable disease. Working with partners/agencies across the world, the 2008–2013 plan focuses on cardiovascular diseases, diabetes, cancer, and chronic respiratory disease, as well as the four shared risk factors of tobacco use, physical inactivity, unhealthy diet, and the harmful use of alcohol. The six objectives of the action plan are:

- To raise the priority accorded to noncommunicable disease in development work at global and national levels, and to integrate prevention and control of such diseases into policies across all government departments
- To establish and strengthen national policies and plans for the prevention and control of noncommunicable diseases

- To promote interventions to reduce the main shared modifiable risk factors for noncommunicable diseases—tobacco use, unhealthy diet, physical inactivity, and harmful use of alcohol
- To promote research for the prevention and control of noncommunicable diseases
- To promote partnerships for the prevention and control of noncommunicable diseases
- To monitor noncommunicable diseases and their determinants and evaluate progress at the regional, national, and global levels (WHO, 2008)

### **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 in making appropriate treatment decisions. Cochrane was 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 clinical 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. It also hosts the Cochrane Library, which is a sophisticated collection of databases containing current, high-quality research that supports practice.

However, evidence-based practice does not rely on RCTs alone. A number of definitions have been brought forth, but Porter-O’Grady (2006) offers a clear and succinct definition: “Evidence-based practice is simply the integration of the best possible research to evidence with clinical expertise and with patient needs. Patient needs in this case refer specifically to the expectations, concerns, and requirements that patients bring to their clinical experience” (p. 1).

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 a sample 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))
- The Joanna Briggs Institute ([www.joannabriggs.edu.au](http://www.joannabriggs.edu.au))
- 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 healthcare

delivery system: the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act expand, 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:

- It established a Patient’s Bill of Rights.
- High-risk insurance pools were created to make insurance available to individuals with pre-existing health conditions until healthcare coverage exchanges are operational in 2014.
- Insurers are no longer able to exclude children with pre-existing 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 pre-existing 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 copays 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 will be available to those whose income is above Medicaid eligibility and 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; The White House, 2011)

## SUMMARY

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The United States touts the most sophisticated and technologically advanced health care in the world. Such health care should produce optimal patient outcomes rivaled by none. With health-care expenditures amounting to 17.6% of the GDP, apparently sophisticated health care comes at a price. Currently the United States spends \$8,086 per capita to provide this care. However, even with all of the money that the nation has allocated to health care, outcomes are not optimal. When compared with the countries in the OECD, the United States ranks below the median on most core measures while having the most expensive health care in the world. Life expectancy of 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?

## STUDY QUESTIONS



Summarize the state of chronic disease in the United States and globally today.

What factors and influences have led to the increased incidence of chronic disease in the United States?


What factors should be considered in defining chronicity?

How can we better educate healthcare professionals to care for those with chronic disease? To care for older adults with chronic disease?

What changes does the healthcare delivery system need to embrace to better care for those with chronic disease?

Compare and contrast chronic disease and chronic illness.

What action should the United States take to decrease healthcare disparities?



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