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Impact of the Disease

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Chronicity

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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), 2008a], 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. However, perhaps more sobering are the CDC's (2008a) data that have quantified the costs from chronic disease.

- The direct and indirect costs of diabetes is \$174 billion per year
- In 2008, the cost of heart disease and stroke is projected to be \$448 billion
- Cancer costs the United States \$89 billion annually in direct medical costs; and finally
- 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, 2008a)

These facts indicate that chronic disease is the nation's greatest healthcare problem and the number one driver of health care today. With our aging population and our advanced technologies that

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

The prevalence of chronic disease worldwide is similar if not greater than that of chronic disease in the United States. Chronic diseases are the leading cause of death in the world (World Health Organization [WHO], 2005a; Yach, Hawkes, Gould, & Hofman, 2004). 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, 2005, p. 18–20).

There is a wide variety of conditions that are considered chronic, and with each condition a diverse array of services is needed to care for these 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 would need different types of services from a healthcare system that is currently attuned to delivering acute care.

The first baby boomer turns 65 in 2011, and this anticipated 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.

The influx of baby boomers into organizations such as AARP has distinctly flavored the activities of that organization. In addition, this new group of seniors will be the most ethnically and racially diverse of any previous generation (National Center for Health Statistics, 2007). In 2003, 83% of American older adults were non-Hispanic white; by 2030 that percentage will decrease to 72% (CDC & Merck Company, 2007). Unfortunately, the healthcare disparities that we have seen in the past with regard to ethnic and racial groups are not decreasing, but increasing. The 2007 National Health Disparities Report found that across all core measures, the number of measures of quality and access where disparities existed in 2000 to 2001 grew larger in 2004 to 2005 (Agency for Healthcare Research and Quality [AHRQ], 2008). 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, bacteriology, immunology, 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 benefitted 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 by healthcare professionals, there is a distinguishable difference between them. Disease refers to a condition that is viewed from a pathophysiologic model, 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 and their families. Although it is important to recognize the pathophysiologic process of a chronic disease, understanding the illness experience is essential in 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).

This excerpt from an article chronicles part of the illness experience for this caregiver and her husband with multiple sclerosis. The illness experience is nursing's domain. Therefore, the focus of this book is on the illness experience of individuals and families, and not specific disease processes.

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 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 (Table 1-1). 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; non-pathologic alteration; required rehabilitation; or a long period of supervision, observation, and care (Mayo, 1956). The National Conference on Care of the Long-Term Patient added a time dimension to these characteristics: chronic disease or impairment necessitating acute hospitalization exceeding 30 days, or medical supervision and rehabilitation of 3 months or longer in another care setting (Roberts, 1954).

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. A teenager may require greater adjustment than an older adult to the limitations necessitated by bone cancer. The degree of disability and altered life style, 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

TABLE 1-1

Definitions of Chronic Disease and Chronic Illness

<i>Author</i>	<i>Definitions</i>
Commission on Chronic Diseases (1956)	All impairments or deviations from normal that have one or more characteristics: are permanent, leave residual disability, are caused by nonreversible pathologic alteration, require special training of the patient for rehabilitation, and may be expected to require a long period of supervision, observation, or care
Feldman (1974) [summarized]	Ongoing medical condition with spectrum of social, economic, and behavioral complications that require meaningful and continuous personal and professional involvement [summarized]
Cluff (1981)	A condition not cured by medical intervention, requiring periodic monitoring and supportive care to reduce the degree of illness, maximize the person's functioning and their responsibility for self-care [summarized]
Curtin & Lubkin (1995)	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

their own right, making them eligible to be defined as a chronic illness. For example, this situation is represented by 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 intestinal cancer when an individual was 30 years of age can contribute to a malabsorption problem years later, so that continuous diarrhea results in a now cachectic and exhausted person. 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 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 their impact on society in general.

Other chapters in the book address the effect on the individual and family, for example, stigma, social isolation, and body image.

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, Director of the CDC states “the aging of the US population is one of the major public health challenges we face in the 21st century” (CDC & Merck Company, 2007). In 2006 persons older than 65 years of age numbered 37.3 million, and represented 12.4% of Americans (Administration on Aging, 2007). Since 1900, the percentage of older Americans has tripled. By 2030 there will be 71.5 million adults in the United States who are older than age 65 years, nearly double the current number and roughly 20% of the US population (CDC & Merck Company, 2007). The longer life spans of Americans and the aging baby boomers are contributing to these demographic changes.

The *State of Aging and Health in America 2007* (CDC & Merck Company, 2007) reports that 80% of older Americans have at least one chronic health condition. The most frequently occurring conditions in 2004 to 2005 included hypertension (48%); diagnosed arthritis (47%); all types of heart disease (29%); any cancer (20%); diabetes (16%); and sinusitis (14%) (Administration on Aging, 2007). Medicare data document that 83% of all of their 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. What will the needs of these aging adults mean to 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.

Lynn and Adamson (2003, p. 9) discuss a trajectory model of caring for older adults with serious chronic illnesses. The first trajectory is the “short period of evident decline.” A chronic condition most typical of this trajectory is cancer. Individuals are treated initially, but when the illness becomes overwhelming, patients cease treatment and hospice care is a common end result of this trajectory.

The second trajectory is “long-term limitations with intermittent exacerbations and sudden dying.” This type of trajectory is common with individuals who have organ system failure. Disease management, advance care planning, and mobilizing services to home are key to care. The last trajectory is “prolonged dwindling.” Conditions typical of this trajectory are dementia, disabling stroke, and frailty (Lynn & Adamson, 2003, p. 9).

Lynn and Adamson’s (2003) trajectory is different from how older adults with chronic illness were viewed previously. Typically there was a steep decline in health status, and older adults either got better or died. However, even the concept of dying has become less clear (p. 8). With more advanced technology and further developments in palliative care, there may not be an identified “time” that we can determine when a client is “terminally ill,” and will thus move into the hospice trajectory. Lynn

and Adamson (2003) state that older adults with chronic illness should expect the following from a care system: correct medical treatment, reliable symptom relief, no gaps in care, no surprises in the course of care, customized care, consideration for family situation, and help as needed to make the best of every day (p. 15).

The Healthcare Delivery System

The current healthcare system was largely designed and shaped in the two decades following World War II (Lynn & Adamson, 2003). In 1946, Congress passed P.L. 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 to 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 is certainly not managing the illness experience of the client and family. No one component 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 need to 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. Let’s

apply an older adult to this scenario: 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 chronic conditions, but there is no coordinator of his care. He is taking multiple medications, and soon he becomes confused and incontinent. What does our acute care system do with this older adult with multiple chronic health problems? 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. How does our healthcare delivery system care for Mr. Jones and the multitude of others like him on the horizon?

Healthy People 2010

The effect of chronic disease across the United States has prompted a national approach to prevention and management of chronic disease. *Healthy People 2000* and now *Healthy People 2010* are the result of the influence of chronic disease, but they are also interventions to the problems of chronic illness.

The objectives of *Healthy People 2010* are based on two overarching goals: (1) increase the quality and years of healthy life; and (2) eliminate health disparities among subgroups of the population. These goals are being monitored through 467 objectives in 28 focus areas. Many of the objectives focus on interventions designed to reduce or eliminate illness, disabilities, and premature death among individuals and communities. Furthermore, many of the focus areas relate to chronic disease and/or prevention of chronic disease (Table 1-2).

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/or books have evolved from that initiative.

TABLE 1-2

Healthy People 2010 Focus Areas

- Access to quality health services
- Arthritis, osteoporosis, and chronic back disorders
- Cancer
- Chronic kidney disease
- Diabetes
- Disability and secondary conditions
- Educational and community-based programs
- Environmental health
- Family planning
- Food safety
- Health communication
- Heart disease and stroke
- HIV
- Immunization and infectious diseases
- Injury and violence prevention
- Maternal, infant, and child health
- Medical product safety
- Mental health and mental disorders
- Nutrition and overweight
- Occupational safety and health
- Oral health
- Physical activity and fitness
- Public health infrastructure
- Respiratory diseases
- Sexually transmitted diseases
- Substance abuse
- Tobacco use
- Vision and hearing

Source: Department of Health and Human Services. (2000). *Healthy People 2010. A systematic approach to health improvement*. Retrieved from http://www.health.gov/healthypeople/Document/html/uih/uih_2.htm

Perhaps the most known of those include *Crossing the Quality Chasm* (released in March of 2001) and *To Err is Human* (released in November of 1999). The intent of these documents and others was to improve the health outcomes of individuals in the nation. The IOM's definition of quality is "the degree to which health services for individuals and populations increased the likelihood of desired

health outcomes and are consistent with current professional knowledge” (IOM, 2006). Since 2003, the AHRQ with the Department of Health and Human Services (DHHS) has reported on quality measures. The National Healthcare Quality Report (NHQR) examines 218 measures across four dimensions on quality that include effectiveness, patient safety, timeliness, and patient centeredness. The 2007 report focuses on 41 core measures from which three themes evolved:

- Healthcare quality continues to improve, but the rate of improvement has slowed;
- Variation in quality of health care across the nation is decreasing, but not for all measures;
- The safety of health care has improved since 2000, but more needs to be done (AHRQ, 2008a, p. 1).

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

- The percentage of heart attack patients who were counseled to quit smoking has increased from 42.7% in 2000 to 90.9% in 2005. In addition, 48 states, Puerto Rico, and the District of Columbia all performed above 80% on this measure in 2005; however,
- In 2000, patients with diabetes in the worst performing state versus the best performing state were admitted to the hospital 7.6 times more often with their diabetes out of control. By 2004, this difference had doubled to 14 times. If all states had reached the level of the top four best performing states, at least 39,000 fewer patients would have been admitted for uncontrolled diabetes in 2004, with a potential cost savings of \$216.7 million (AHRQ, 2008a, p. iv).

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 added *State Snapshots* to their website in 2005 (<http://statesnapshots.ahrq.gov/snaps07/index.jsp>). This Web site documents the quality measures of each individual state.

Health Disparities

The second goal of *Healthy People 2010* is to eliminate health disparities in a subgroup of the population based on characteristics such as race and ethnicity, sex, and income or education (Keppel, Bilheimer, & Gurley, 2007). Unfortunately, progress on this goal is slow. The publishing of the book *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Smedley, Stith, & Nelson, 2003) opened the eyes of many to the inequities that minority populations may face in accessing and receiving health care. Of particular note were the disparities seen in cardiovascular health.

Not coincidentally, the first National Healthcare Disparities Report sponsored by AHRQ was released in the same year that *Unequal Treatment* was published. The fifth national report on health disparities (AHRQ, 2008b), released in February 2008, examines 42 measures of quality and 8 measures of access across a number of racial, ethnic, and socioeconomic priority groups and a comparison group. Three themes emerge from the data:

- Overall, disparities in healthcare quality and access are not getting smaller
- Progress is being made, but many of the biggest gaps in quality and access have not been reduced;
- The problem of persistent uninsurance is a major barrier to reducing barriers (AHRQ, 2008b, p. 1)

Although there has been some progress made, that is, disparity between black and white hemodialysis patients with adequate treatment has been

eliminated, there are a number of areas where healthcare delivery disparities in the United States has worsened considerably. The biggest disparities include the following:

- Blacks had a rate of new AIDS cases 10 times higher than that of whites.
- The proportion of black children who were hospitalized because of asthma was almost four times higher than that of white children.
- Asian adults age 65 years and older were 50% more likely than whites to lack immunization against pneumonia.
- American Indians and Alaska Natives were twice as likely as whites to lack prenatal care in the first trimester.
- Hispanics had a rate of new AIDS cases more than 3.5 times higher than that of non-Hispanic whites.
- Poor children were more than 28% more likely than high income children to experience poor communication with their healthcare providers (AHRQ, 2008b, p. 8).

Culture

Illness belief systems form a cultural milieu that define 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 Chapter 12).

Another way to view culture is to consider chronic illness as a culture. Although we often believe that each disease process is "different," there are multiple tasks that are similar, although not the same, and illness experiences may look alike across diseases. Strauss (1975), and again with other colleagues (Strauss et al., 1984), 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. Nearly 25 years ago, Strauss and colleagues (1984) suggested that the basic strategy to cope with these issues was to normalize, not just to stay alive or keep their symptoms under control, but to live as normally as possible (p. 79).

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 presented themselves. Clearly the class was able to see the culture of what it was like to have a chronic illness and to understand the vast number of similarities between individuals with totally different 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 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.), a diagnosis of AIDS, and so forth. Yes, the advertisements of department stores with individuals in wheelchairs may help, but 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 increased 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 6.7% to \$2.1 trillion, or \$7026 per person in 2006 (Catlin, Cowan, Hartman, Heffler, & National Health Expenditure Accounts Team 2008), the most current year for which data are available. However, the good news is that the rate was only slightly higher than the 6.5% growth that was seen in 2005, which was the slowest growth since 1999. Currently, healthcare spending accounts for 16.0% of the gross domestic product (GDP), up from 15.9% in both 2004 and 2005. Despite growth in prescription drug spending and this slight increase in healthcare spending, most major health services and public payers experienced slower growth in 2006 (pp. 20–21).

Catlin and colleagues (2008) note several important findings, particularly with prescription drugs in 2006. After 6 years of slowed growth, prescription drug spending growth accelerated in 2006. This occurred at the same time as the implementation of Medicare Part D, which caused major shifts in the sources of funds that paid for drugs. These shifts and movement toward more enrollment in Medicare-managed care plans caused growth in Medicare's administrative and net cost of insurance to increase (p. 15). The impact of Medicare Part D on overall national healthcare spending in 2006 was modest; however, the public share of drug spending increased from 28% in 2005 to 34% in 2006, whereas the private share fell from 72% to 66% (p. 19).

As a nation, the United States continues to outspend other countries in the Organization for Economic Cooperation and Development (OECD)

at a rate that is 2.5 times that of the median OECD country (Anderson, Frogner, & Reinhardt, 2007). However, with the highest healthcare spending rate, the United States continues to provide less access to healthcare resources when compared with the 29 industrialized countries in the OECD (p. 1481), as individuals of lower socioeconomic status and some minority groups have a more difficult time accessing healthcare resources.

CDC's National Center for Chronic Disease Prevention and Health Promotion has provided some quick facts about the economic burden of chronic disease in this country (Table 1-3). Included in this table are two major factors that contribute to chronic disease: obesity and tobacco use.

Using Medical Expenditure Panel Survey (MEPS) data, five conditions have been identified as the most costly conditions in the non-institutionalized population, and four of them are chronic conditions. The five conditions—heart disease, cancer, trauma-related disorders, mental disorders, and pulmonary conditions—ranked highest in terms of direct medical spending in 2000 and again in 2004 (Soni, 2007). These data are based on expenditures (what is paid for healthcare services), and does not include any indirect costs. Heart disease had the largest medical expenditures in 2004 with 10%, followed by cancer at 6.9%, trauma-related disorders at 6.5%, mental disorders at 5.8%, and pulmonary conditions at 5.4% (Soni, 2007).

Compounding chronic disease and the aging population 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 (most current available) demonstrate the following in the population younger than 65 years of age:

- 17.4 million US residents younger than 65 years of age were uninsured for the entire 4-year period (2002 through 2005).
- Those reporting fair/poor health were the most likely to be uninsured (11.2%) for the entire 4-year period.

TABLE 1-3**Quick Facts: Economic and Health Burden of Chronic Disease**

<i>Disease/Risk Factors</i>	<i>Morbidity (Illness)</i>	<i>Mortality (Death)</i>	<i>Direct Cost/Indirect Cost</i>
Arthritis	Arthritis affects 1 in 5, or 46 million, US adults, making it one of the most common chronic conditions. More than 40%, or nearly 19 million, adults with arthritis are limited in their activities because of their arthritis. By 2030, nearly 67 million (25%) of US adults will have doctor-diagnosed arthritis. In addition, adults with arthritis-attributable activity limitation are projected to increase from 16.9 million (7.9%) to 25 million (9.3% of the US adult population) by 2030.	From 1979 to 1998, the annual number of arthritis and other related rheumatic conditions (AORC) deaths rose from 5537 to 9367. In 1998, the crude death rate from AORC was 3.48 per 100,000 population.	The total costs attributable to arthritis and other rheumatic conditions AORC in the United States in 2003 was approximately \$128 billion (\$80.8 billion in medical care expenditures and \$47 billion in earnings losses). This equaled 1.2% of the 2003 US gross domestic product.
Cancer	About 1.3 million people in the United States are diagnosed with cancer each year.	Cancer is the second leading cause of death in the United States. In 2004, an estimated 553,000 people died of cancer.	The NIH estimated the overall costs for cancer in the year 2007 at \$219 billion: of this amount, \$89 billion for direct medical costs and \$130 billion for indirect costs such as lost productivity.
Diabetes	More than 20.8 million Americans have diabetes, and about 6.2 million don't know that they have the disease.	Diabetes is the sixth leading cause of death. More than 200,000 people die each year of diabetes-related complications.	The estimated economic cost of diabetes in 2007 was \$174 billion. Of this amount, \$116 billion was the result of direct medical costs and \$58 billion, indirect costs such as lost workdays, restricted activity, and disability caused by diabetes.
Heart disease and stroke	More than 80 million Americans currently live with a cardiovascular disease.	More than 870,000 Americans die of heart disease and stroke each year, which is about 2400 people dying each day.	The cost of heart disease and stroke in the United States in 2008 is projected to be more than \$448 billion, including direct and indirect costs.

(Continued)

TABLE 1-3**Quick Facts: Economic and Health Burden of Chronic Disease (Continued)**

<i>Disease/Risk Factors</i>	<i>Morbidity (Illness)</i>	<i>Mortality (Death)</i>	<i>Direct Cost/Indirect Cost</i>
Overweight/obesity	In 2005 to 2006 more than 34% of adults aged 20 years or older, were obese. More than 125 million or 17.1% of children and adolescents 2 to 19 years of age are overweight.	The latest study from CDC scientists estimates that about 112,000 deaths are associated with obesity each year in the United States.	Direct health costs attributable to obesity have been estimated at \$52 billion in 1995 and \$75 billion in 2003. Among children and adolescents, annual hospital costs related to overweight and obesity more than tripled over the last two decades.
Tobacco	An estimated 45.3 million adults in the United States smoke cigarettes, even though this single behavior will result in death or disability for half of all regular users.	Tobacco use is responsible for approximately 438,000 deaths each year.	The economic burden of tobacco use is enormous: more than \$96 billion in medical expenditures and another \$97 billion in indirect costs.

Source: Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Retrieved on January 31, 2008 from <http://www.cdc.gov/nccdphp/press/index.htm>

- Hispanics were disproportionately represented among the long-term uninsured. Although they represented only 15.7% of the US population during this period, they represented 40.1% of the long-term uninsured.
- Individuals who were poor were disproportionately represented among the long-term uninsured. Although representing 13.2% of the population younger than age 65 years, they represented 25.6% of the long-term uninsured (Rhoades & Cohen, 2007).

In individuals older than 65 years of age, only 1% of noninstitutionalized adults did not have insurance coverage of some kind. In 2006, Medicare covered 94% of noninstitutionalized older adults (Administration on Aging, 2007). Medicare covers mostly acute care services and requires that beneficiaries pay nearly half of all of

their healthcare expenses. Approximately 61% of those older than 65 years had some type of private health insurance, 7% had military-based health insurance, and 9% were covered by Medicaid (Administration on Aging, 2007).

When looking at the costs of chronic disease, one needs to identify the lost productivity of the individual and/or family affected, as well as the number of health resources used. The American Diabetes Association (ADA) has developed a model for diabetes that identifies lost productivity as well as the monetary costs. Through a prevalence-based model utilizing epidemiologic data, healthcare costs, and economic data, a cost of diabetes model was developed. The total estimated cost for diabetes in 2007 was \$174 billion dollars, with \$116 billion in medical expenditures and \$58 billion in decreased productivity, either by the individual or the family caregiver (American Diabetes Association, 2008).

Of note are the costs that are *not* included in the \$174 billion. Those include: healthcare system administrative costs, over-the-counter medications, care provided by nonpaid caregivers, excess medical costs associated with undiagnosed diabetes, and so forth (p. 1).

In summary, the financial impact of chronic disease is large. With the changing demographics of the population and the incidence of chronic disease, the impact will increase.

INTERVENTIONS

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 what the United States is doing to eliminate the impact of chronic disease.

Professional Education

One of the challenges in chronic disease care and management is educating healthcare professionals about caring for those individuals. 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 has 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* (2005b), 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 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 1-4). At first glance, the competencies don’t seem unique. However, in an acute care healthcare delivery system, these concepts aren’t as prominent. Clients are

TABLE 1-4

WHO Core Competencies

Patient-centered care	<ul style="list-style-type: none"> Interviewing and communicating effectively Assisting changes in health-related behaviors Supporting self-management Using a proactive approach
Partnering	<ul style="list-style-type: none"> Partnering with patients Partnering with other providers Partnering with communities
Quality improvement	<ul style="list-style-type: none"> Measuring care delivery and outcomes Learning and adapting to change Translating evidence into practice
Information and communication technology	<ul style="list-style-type: none"> Designing and using patient registries Using computer technologies Communicating with partners
Public health perspective	<ul style="list-style-type: none"> Providing population-based care Systems thinking Working across the care continuum Working in primary health care–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 and out of the care system quickly, and there is less need for implementation of these concepts.

Chronic Disease Practitioner Competencies

From another point of view, the National Association of Chronic Disease Directors (NACDD) has developed competencies for chronic disease practice. This organization was founded in 1988 to link the directors of chronic disease programs in each state and US territory. These competencies assist state and local healthcare programs to develop both 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 1-5 lists the competencies for chronic disease practitioners.

Resources

Since the publication of the previous edition of this book, two of the entities that provided education about chronic disease and recommendations for practice (and were referenced in the prior edition) are no longer in business. The Partnership for Solutions, jointly funded by the Robert Wood Johnson Foundation and Johns Hopkins University, no longer exists, as the Robert Wood Johnson Foundation is not providing funding. The other group that no longer exists is the National Chronic Care Consortium. Their Web site states “the consortium went out of business the summer of 2003.” Both of these organizations provided leadership in caring for those with chronic illness.

Institute of Medicine

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, since 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).

TABLE 1-5**National Association of Chronic Disease Directors Competencies for Chronic Disease Practice***Domain 1—Build Support*

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.

Domain 2—Design and Evaluate Programs

Chronic disease practitioners develop and implement evidence-based interventions and conduct evaluation to ensure on-going feedback and program effectiveness.

Domain 3—Influence Policies and Systems Change

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.

Domain 4—Lead Strategically

Chronic disease practitioners articulate health needs and strategic vision, serve as a catalyst for change and demonstrate program accomplishments to ensure continued funding and support within their scope of practice.

Domain 5—Manage People

Chronic disease practitioners oversee and support the optimal performance and growth of program staff as well as themselves.

Domain 6—Manage Programs and Resources

Chronic disease practitioners ensure the consistent administrative, financial, and staff support necessary to sustain successful implementation of planned activities and build opportunities.

Domain 7—Use Public Health Science

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 April 17, 2008 from www.chronicdisease.org/files/public/complete_draft_Competencies_for_Chronic_Disease_Practice.pdf

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

Healthy People 2010

All 467 objectives of *Healthy People 2010* were examined in 2005 as part of the midcourse review.

On the basis of an evaluation of each objective and comments received from the public as part of the review, 28 objectives were deleted because data were not available or because of a change in science (*Healthy People 2010: Midcourse Review, 2005*). Overall, 29 objectives met the target; 138 objectives moved toward the target; 40 objectives demonstrated mixed progress (in their sub-objectives); 17 objectives were unchanged from the baseline; and 57 objectives moved away from the target.

The midcourse review of focus area 12, heart disease and stroke, is described as one example. The goal of focus area 12 is to improve cardiovascular health and quality of life through prevention, detection, and treatment of risk factors; early identification and treatment of heart attacks and

strokes; and prevention of recurrent cardiovascular events. There are 16 sub-objectives in this focus area. Overall, one objective met or exceeded the target; six moved toward the target; one demonstrated no change; one demonstrated mixed progress; one moved away from the target; and six could not be assessed (see Table 1-6).

Centers for Disease Control and Prevention Programs

The CDC has provided both leadership and funding in developing state-based programs nationwide. Programs have been developed to look at both risk factors and prevention of disease, as well as examine ways to prevent complications and delay death resulting from chronic disease. One example of CDC's 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 is providing.

Diabetes. *Promoting Effective State Programs.* In 2007 the CDC provided funding for capacity building to 22 states, 8 current or former US 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. These state programs identify the disease burden in their states, develop and evaluate new prevention strategies, establish partnerships, increase awareness of prevention and control opportunities, and improve access to quality care (CDC Diabetes, 2008).

Monitoring the Burden and Translating Science. 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 (CDC Diabetes, 2008).

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 comprises more than 200 public and private partners to increase knowledge about diabetes. In addition, CDC is working to target populations at risk (CDC Diabetes, 2008).

Supporting Primary Prevention. The Diabetes Prevention Program (DPP) was a CDC clinical trial demonstrating that sustained lifestyle changes could reduce the progression to type 2 diabetes among adults who were at high risk. The results from this study were so compelling that the study was ended a year early (CDC Diabetes, 2008).

Targeting Populations at Risk. The CDC has developed primary prevention programs for those most at risk for diabetes in five states. The CDC is working in communities with American Indians and Alaska Natives to develop culturally appropriate interventions for those populations (CDC Diabetes, 2008).

REACH. The CDC's Racial and Ethnic Approaches to Community Health (REACH) 2010 program is a community-based public health program that is working to eliminate health disparities in 40 communities of color across the United States (Liburd, Giles, & Mensah, 2006). Within these 40 communities, the CDC supports local coalitions in designing, implementing, and evaluating community-driven strategies to eliminate health disparities. The coalitions use local data to develop individual community based plans. As an example, the Bronx Health REACH project developed a seven-point advocacy agenda intended to eliminate the root causes of health disparities in the southwest Bronx. Their coalition is working to achieve "universal health insurance, an end to segregation in healthcare facilities based on insurance status, accountability for state uncompensated care fund,

TABLE 1-6**Heart Disease and Stroke: Midcourse Review of Objectives Met**

<i>Category</i>	<i>Objective numbers</i>	<i>Description</i>
Objectives that exceeded the target		No objectives exceeded the target
Objectives that met the target	12-14	High blood cholesterol levels: 17% 17% of persons 20 years of age and older had high total blood cholesterol levels (down from 21% in 1988 to 1994)
Objectives that moved toward their target	12-1	Coronary heart disease death rate Death rate dropped from 203/100,000 to 180/100,000 (target is 162)
	12-7	Stroke death rate Death rate from 62/100,000 to 56/100,000 (target is 50)
	12-10	High blood pressure control 64% of the population achieved control in blood pressure (target is 68%)
	12-11	Action to help control blood pressure 93% of the population took action to control high blood pressure (target is 98%)
	12-13	Mean total blood cholesterol levels Total cholesterol levels were reduced from 206 to 203 (target is 199)
	12-15	Blood cholesterol screening 73% of adults 18 and older had cholesterol screenings up from 67% (target is 80%)
Objectives that demonstrated no change	12-12	Blood pressure monitoring for those with high blood pressure remained constant at 90% (target is 95%)
Objectives that moved away from their target	12-6b	Heart failure hospitalizations for persons aged 75 to 84
	12-9	Proportion of persons aged 20 and older with high blood pressure
Objectives that could not be assessed	12-2	Measure knowledge of heart attack symptoms and calling 911
	12-3a	Receipt of artery-opening therapy
	12-3b	Use of percutaneous intervention within 90 minutes
	12-4	Cardiopulmonary resuscitation training
	12-8	Knowledge of early stroke
Objectives that remain developmental	12-5	Out-of-hospital care for cardiac arrest
	12-16	LDL cholesterol levels in CHD patients

Source: *Healthy People 2010*. (2005). Midcourse Review. Retrieved March 6, 2007 from <http://www.cdc.gov/DHDSP/library/hp2010/objectives.htm>

culturally competent care for greater health workforce diversity, an expansion of public health education, and environmental justice” (Calman, 2005, p. 491).

Agency for Healthcare Research and Quality

AHRQ sponsors a number of programs that are working to reduce or eliminate health disparities. The reason that these programs are mentioned is because, as previously noted, 80% of US healthcare dollars are spent on chronic disease. Therefore, healthcare inequities largely involve chronic care.

The Federal Collaboration on Health Disparities Research (FCHDR) is identifying and supporting research priorities for cross-agency collaboration to hasten the elimination of health disparities. The Health Disparities Roundtable is a public-private partnership on research and policy. The Disparity Reducing Advances Project is identifying strategies for bringing health gains to poor and underserved populations. The Think Cultural Health website offers the latest resources and tools to promote cultural competency. The AHRQ National Health Plan Collaborative wants to reduce disparities among 87 million enrollees in health plans. The AHRQ Learning Partnership to Decrease Disparities in Pediatric Asthma identifies areas of need and then makes the case to state governments for further action on asthma disparities. The AHRQ Hispanic Diabetes Disparities Learning Network in Rural and Urban Community Health Clinics focuses on diabetes in adult Hispanics (AHRQ, 2008).

Evidence-Based Practice

In recent years, issues of quality and safety for patients have come to the forefront, with an emphasis on improving health care. The IOM book, *Health Professions Education: A Bridge to Quality* (Greiner & Knebel, 2003) lists five essential competencies for quality care, and one of those

is “employ evidence based practice” (Greiner & Knebel, 2003).

The evidence-based practice movement had its beginnings in the 1970s with Dr. Archie Cochrane, a British epidemiologist. In 1972, he published a book that criticized physicians for not conducting rigorous reviews of evidence to make appropriate treatment decisions. Cochrane was a proponent of randomized clinical trials, and in his exemplar case noted that thousands of low birthweight premature infants died needlessly while at the same time there were several randomized clinical trials (RCTs) that had been conducted on the use of corticosteroid therapy, but the data had never been reviewed or analyzed. After review, these studies demonstrated that use of this therapy reduced infant deaths significantly. Cochrane died in 1988, but as a result of his influence and call for systematic review of the literature, the Cochrane Center was launched in Oxford, England, in 1992. It is known as the Cochrane Library Database, currently the most sophisticated database available of current research that supports practice.

However, it is accepted knowledge that evidence-based practice does not rely on RCTs alone. A number of definitions have been brought forth, but Porter-O’Grady’s succinct definition makes the most sense. “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” (Porter-O’Grady, 2006, p. 1).

DiCenso, Guyatt, and Ciliska (2005) add that clinical expertise is “our ability to use clinical skills and past experience to identify the health state of patients or populations, their risks, their preference and actions, and the potential benefits of interventions” (p. 5).

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 just a sample of the resources available:

- Agency for Healthcare Research and Quality (AHRQ)—the United State’s premier evidence-based practice agency: [//www.ahrq.gov](http://www.ahrq.gov)
- Cochrane Library: www.cochrane.org
- Task Force on Community Preventive Services: www.thecommunityguide.org
- US Preventive Services Task Force: www.ahrq.gov/clinic/uspstfab.htm
- Veterans Evidence-Based Research Dissemination Implementation Center (VERDICT): www.verdict.research.va.gov/
- National Guideline Clearinghouse: www.guideline.gov
- British Medical Journal & United Health Foundation: www.clinicalevidence.com

Legislation

National surveys of 1238 physicians, 1663 Americans, and a convenience sample of 155 policy makers were asked their perceptions of how well the current healthcare delivery system addresses the needs of individuals with chronic conditions (Anderson, 2003). Compared with the public and the physicians, policymakers were more pessimistic about the healthcare system. A majority of all three groups agreed that it is somewhat or very difficult for individuals with chronic conditions to obtain adequate care (p. 437).

Changing public policy continues to be a primary intervention in assisting clients and their families with chronic conditions. Institution of national policies and the financing of prevention and health promotion need to occur. In addition, until healthcare professionals are able to make a difference in the agency maze and the financing of that maze, clients will continue to have difficulty accessing the chronic long-term care that they need (see Chapter 23).

Research

Although research on chronicity continues to increase, there is a continuing need to demonstrate new paradigms of caring for those with chronic illness. What follows are examples of studies that may be useful in caring for those with chronic illness.

Advanced Practice Nursing Interventions

McCauley, Bixby, and Naylor (2006) designed an RCT that examined the effectiveness of advanced practice nurse (APN) interventions in increasing length of time between hospital discharge and readmission or death, reducing readmissions, and decreasing overall healthcare costs in clients with heart failure (HF). Their original work looked at a one-month intervention, but follow-up deemed that the duration was far too short. Their latest study looked at a nursing home care intervention at 3 months and included APNs with more HF experience. Thus they were able to demonstrate improved outcomes for up to 1 year after the acute episode of HF. Interventions focused on individualized patient assessment, enhanced patient-provider communication, targeted interventions to improve self-management, and improved access to resources. Although the primary focus of the study was HF, most clients had multiple, active comorbid conditions that complicated their HF and put them at risk for poor outcomes. The study produced statistically significant results and demonstrated that the APNs were effective in reducing rehospitalizations related to these comorbid conditions (McCauley et al., 2006).

Another nursing intervention study with patients with HF was carried out by Sisk and colleagues (2006). An RCT was conducted with HF patients in four hospitals in Harlem, New York, working with a mostly black or Hispanic population of 406 adults. During a 12-month intervention, bilingual nurses counseled patients on diet, medication adherence, and self-management of symptoms through an initial visit and then regularly scheduled follow-up phone calls, and contact with their physicians as well. The outcome

measures of the study were re-hospitalizations and self-reported functioning. Both outcome measures had better results and were significantly different than the “usual care” clients (Sisk et al., 2006).

Hamner (2005) published a state-of-the-science review of studies of interventions in which nurses played a major role in the outcomes of patients with HF. Hamner categorized the research as (1) home-based nursing interventions, (2) nurses in pivotal roles in multidisciplinary interventions that extended to the home, (3) heart failure clinics, and (4) telephone- or technology-based nursing interventions. The home-based intervention studies included five RCTs with 569 patients. There were mixed results, with some of the studies showing improved self-care behavior, whereas others did not; some of the studies showed decreased re-hospitalization rates and others did not.

In the multidisciplinary intervention studies, more positive results were obtained in the studies (mostly RCTs, again) of 1879 patients. Results demonstrated decreased lengths of stay, decreased admissions and re-admissions, decreased costs, decreasing mortality, longer event-free periods and improved quality of life (QOL) (Hamner, 2005).

Ten studies focusing on an extended role of nursing in HF clinics demonstrated convincing evidence that HF clinics that included a strong nursing role are effective in reducing hospital admission and emergency department visits, decreasing mortality, improving self-care and QOL, and reducing costs. Only one study in this group did not show positive outcomes (Hamner, 2005).

In the last grouping of four studies on technology- and/or telephone-based home intervention, there were few positive outcomes. Two studies found decreased emergency department visits and one showed increased patient satisfaction, but there were few positive results in studies that included 700 patients (Hamner, 2005).

Health Promotion

Typically, interventional studies of chronic illness have focused on symptom management—what

nursing intervention(s) can be performed to alleviate a physical symptom. From this author’s perspective, that approach views chronic illness through a disease model, or a medical model, and does not address the whole person. Such research is important in the care of those with chronic disease, but there may be another way to view chronic disease, and that is through a wellness lens. Stuifbergen (2006) suggests that it makes sense to develop and test interventions to promote health rather than control the disease of persons with chronic conditions: in other words, conceptualizing health within illness. Three of her studies demonstrate the possibilities of this concept.

An RCT including 113 women with multiple sclerosis operationalized a two-phase intervention program, the Wellness Program for Women with MS, with lifestyle-change classes for 8 weeks and follow-up telephone calls for 3 months. Participants were then followed over an 8-month period. The experimental group had statistically significant differences in self-efficacy for health behaviors, health-promoting behaviors, and the mental health and pain scales of the SF-36 (Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003).

In two small studies of clients with HF, 19 clients reported increased self-perceived health and increased use of health-promoting behaviors (Clark et al., 2006). The intervention used with these clients was modeled after the Wellness Program for Women with MS.

The Future

In 2005, the Surgeon General’s Office disseminated a document entitled *Call to Action to Improve the Health and Wellness of Persons with Disabilities* (Smeltzer, 2007). This document spoke to the need of ensuring that individuals with disabilities can access comprehensive health care so that they can live productive lives (p. 189). Smeltzer (2007) suggests that the amount of research examining individuals with disabilities and appropriate interventions to enhance their health outcomes has not

kept pace with the increasing number of individuals with disabilities. Although we know that individuals with disabilities may have acquired their disability from multiple causes, chronic disease is the major cause/proponent of most of the disabilities.

The IOM (2008) in their report on *Retooling for an Aging America*, suggests that more research is needed that addresses the effective use of the workforce to care for older adults and how to increase both the size and the capabilities of that workforce. In addition, the IOM report recommends that more support be provided for technologic advances that could enhance the capacity to care for older adults.

A growing patient population includes those with chronic critical illness. This population consists of individuals who cross over from acute to chronic critical illness with a syndrome of significant, characteristic derangements of metabolism, neuroendocrine, neuropsychiatric, and immunologic function

(Nelson et al., 2004, p. 1527). Often these individuals make the transition to a chronic condition after having a tracheotomy for failure to wean from mechanical ventilation. How do we assist this population in maintaining QOL? What nursing interventions assist in better outcomes for these chronically ill patients?

OUTCOMES

This chapter has included data from a number of national reports, each with a list of recommendations and benchmarks to improve health outcomes of the population. Perhaps the best known is *Healthy People 2010*. Although we have made progress in meeting some of the benchmarks for chronic disease, much progress is required. Caring for the client and family with chronic disease will continue to be an on-going challenge.

STUDY QUESTIONS

1. What factors and influences have led to the increased incidence of chronic disease in the United States?
2. What factors should be considered in defining chronicity?
3. How can we better prepare healthcare professionals to care for those with chronic disease? To care for older adults with chronic disease?
4. What changes does the healthcare delivery system need to embrace to better care for those with chronic disease?
5. Compare and contrast chronic disease and chronic illness.
6. What action does the United States need to take to decrease healthcare disparities?
7. What should the nursing research foci be related to chronic disease?

INTERNET RESOURCES

British Medical Journal & United Health Foundation: www.clinicalevidence.com

Cochrane Library: www.cochrane.org

National Guideline Clearinghouse: www.guideline.gov

Task Force on Community Preventive Services: www.thecommunityguide.org

Think Cultural Health: www.thinkculturalhealth.org

US Preventive Services Task Force: www.ahrq.gov/clinic/uspstfab.htm

Veterans Evidence-Based Research Dissemination Implementation Center (VERDICT): verdict.uthscsa.edu/verdict/default.htm

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