Aging, Health Care, and Society

Learning Objectives

After reading Basic Concepts II, “Aging, Health Care, and Society,” readers will:

1. Appreciate the significance of both normal aging and chronic illness as these influence later life.
2. Identify the main features of the U.S. systems for delivering health care and long-term care.
3. Understand critical value dilemmas for health care policy in an aging society.

Five hundred years ago, the Spanish explorer Juan Ponce de León embarked on a journey to the New World. Popular legend has it that he was in search of the fountain of youth, but whatever his purpose may have been, he never found the fountain of youth. Instead, he discovered what is today Florida, the state with the largest percentage of older adults. But many discoveries have a way of turning out differently than expected. When we think about medical advances in our time, these also have turned out unexpectedly. For instance, as we discussed in Controversy 2, people are living longer today, but is the prolongation of life into old age always a benefit? Or have recent gains in longevity instead been a prolongation of decrepitude and frailty? Will further medical advances only make matters worse? This question was raised nearly three centuries ago by Jonathan Swift in his satirical novel Gulliver’s Travels (1726).

The Challenge of Longevity

The Case of the Struldbrugs

Swift described a voyage to the fictional country of Luggnagg, where his hero, Lemuel Gulliver, meets a strange group of beings, the “Struldbrugs,” who are a race condemned
to immortality. It turns out that for the Struldbrugs, unlimited life span has not proved the blessing it promised to be. Longevity has come, but without good health. Their existence is a dismal prolongation of decline and decay, as Swift described them:

They were the most mortifying sight I ever beheld. . . . Besides the usual deformities in extreme old age, they acquired an additional ghastliness in proportion to their number of years, which is not to be described . . .

The diseases they were subject to still continue without increasing or diminishing. In talking they forget the common appellation of things, and the names of persons, even of those who are their nearest friends and relations. . . . The least miserable among them appear to be those who turn to dotage, and entirely lose their memories.

In describing the Struldbrugs, Swift raised a question that is still of compelling interest:

The question therefore [is] not whether a man would choose to be always in the prime of youth, attended with prosperity and health, but how he would pass a perpetual life under all the usual disadvantages which old age brings along with it.

No doubt Swift exaggerated to make his point. To speak of the imagined and real disadvantages of old age misses the positive aspects of aging. Today, we see countless examples of older people who are not debilitated or dependent, but who maintain health and vigor into their later years, as well as examples of older people who adapt to and remain optimistic despite significant health challenges. Yet Swift’s vision does raise profound questions about our values. As a beginning, however, we examine several major challenges that people face as they grow older. The first is the challenge of coping with an aging body. Medical advances that help people live longer may seem beneficial, but having more years of life doesn’t necessarily mean those years are without infirmity and disability. The second challenge is that of maintaining a valued place in society while aging. Older people are often stereotyped as marginal members of society though the majority of respondents in a recent national survey felt positively about the growing numbers of older adults in the population (Pew Research Center, 2013). Nevertheless, as the average age in the United States steadily increases, we are beginning to confront questions of when people cross from capable old age to dependency. Finally, as individuals grow older, they do so in the wider context of an entire society that is undergoing a transition to population aging. How we think about and respond to these challenges has implications for individuals and for society.

**Biomedical Advances**

There are those who believe that biomedical advances will save us from these challenges. They argue that biomedical researchers can meet the challenge of longevity by developing techniques for delaying the onset of debilitating conditions in old age. In effect, they hope to postpone sickness until a final, brief period of life and so eliminate prolonged dependency, as discussed regarding compression of morbidity in Controversy 2. Other biologists believe that we can discover a fountain of youth by altering the fundamental biological mechanism that makes us grow old (de Grey & Rae, 2008). Whether by delaying illness or actually preventing biological aging, the scientific optimists believe that the “Struldburg problem” can eventually be solved.
Rationing Health Care

Their optimism is not shared by all. Others believe that hard choices are called for, and they doubt that technological innovations will save us from making those choices. We’d do better, it is said, to acknowledge the biological limits, rather than hope for a technological fix for the problems that often come with aging. In this spirit, ethicist Daniel Callahan (as evidenced in the readings later in this book) wants to reject high-tech medical care used to prolong life for the very old. Instead, he believes, it would be a better use of resources to ration health care on the basis of age. He recommends forgoing life-extending treatment once older people have lived out a full and natural course of life.

Providing Long-Term Care

If more and more members of the population live into advanced old age, we will see growing numbers of frail, chronically ill older adults in need of long-term care, at home or in institutions. The term long-term care covers health care and social services needed by those who have lost the capacity to care for themselves because of a chronic illness or condition. It is expected that growing numbers of older people will suffer from chronic disorders that keep them from living independently. In that case, long-term care will loom even larger in the future than it does today. Opinions differ about who should bear the cost of that care, but paying the bill for longevity is already a serious challenge to society.

Self-Determined Death

Neither prolonged debilitation nor rationing of health care is popular with most Americans. But growing numbers today do feel that decline and a diminished quality of life might be sufficient reasons to no longer live. Some, like Ezekiel Emanuel, believe that age 75 is long enough and there is no need for measures to live longer (Emanuel, 2014). Others go so far as to believe that the losses of advanced age are reason enough to actively end one’s life. Those who hold this view often reject the idea of society setting limits, but would instead leave the choice about dying up to the individual. Advocates of this idea believe that deliberate termination of treatment must be more openly recognized by law and should be actively supported by health care services.

So here we have four responses to the Struldbrug dilemma: hoping for a medical breakthrough, making tough cost-cutting decisions, providing long-term care, and permitting individuals to end their lives. All are ways of coping with the prospect of a prolonged period of frailty and dependency at the end of life. The options considered here are not mutually exclusive. But each raises profound questions about our values: Are the old less valued than the young? Where will we find the resources to take care of frail older adults? Could scientific breakthroughs in the biology of aging have unforeseen consequences for society, either for good or for ill?

These questions have no easy answers. Indeed, they are at the center of the major debates examined in this book. The biology of longevity, the economics of health care, and the right to die are interrelated issues. By appreciating some key facts about biology, economics, and death and dying, we can better approach the debates surrounding these critical issues.

A difficulty arises from the fact that contemporary medical practice in the United States is based on a strategy of curing disease, not promoting health. This familiar strategy has led
to the conquest of many killer diseases, such as smallpox and polio, thus permitting a greater portion of the population to reach old age. Since the 1960s, overall death rates from cardiovascular disease, on an age-adjusted basis, have continued to drop each decade, though there are differential rates according to gender and ethnicity (National Heart, Lung, and Blood Institute, 2012). The net effect of all these interventions has been to raise average life expectancy in the United States from 47 years in 1900 to an all-time high of 79, according to the National Center for Health Statistics.

### URBAN LEGENDS OF AGING

**“We’re living much longer today.”**

We often hear that people are living vastly longer, but is it really true? Life expectancy, for those who reach age 65, has increased by less than 4 years since the mid-20th century (Friedman & Martin, 2011). That’s an increase, but it’s hardly staggering. It’s true that life expectancy at birth went up around 30 years (from 49 to 79) during the 20th century, and that was the greatest gain in history. But the demographic dividend was largely the result of public health interventions early in life, and much less from medical breakthroughs enabling us to live longer lives after age 65. Gains in life expectancy after age 65 are much less dramatic than commonly believed.

### Normal Aging

In a broad sense, one might say that aging begins at birth, but we normally identify aging with changes that come after maturity. Gerontologists often use the term normal aging to describe this underlying irreversible process that is characteristic of all members of each species. Biological aging can be defined as a time-dependent series of cumulative, progressive, intrinsic, and ultimately harmful changes that begin to manifest themselves at reproductive maturity and eventually end in death (Arking, 1998). Primary aging would describe those changes that occur over time independent of any specific disease or trauma to the body, whereas secondary aging would describe disabilities resulting from forces such as disease (Blumenthal, 2003).

The idea of normal aging is important because health care professionals see mainly sick people; as a result, it is easy to develop negative stereotypes about older people. One common stereotype depicts older people as frail and sick. But in fact, the majority of people ages 65 and older are healthy enough to engage in most activities of daily living (ADLs), such as bathing, dressing, and preparing meals. A majority of older adults living in noninstitutional settings report experiencing no significant limitations in performing these regular, daily activities (National Council on Aging, 2015). However, the probability of experiencing limitations increases with age (Administration on Aging, 2015).

### Longevity and Disease

Steps toward health promotion, such as improved diet and increased exercise, can reduce the likelihood of illness and thus increase life expectancy. These steps may also reduce
morbidity—that is, illness or disease—in later life but not invariably so. It is clear that a decline in the mortality rate need not be matched by a decline in morbidity. A recent national survey of adults 60 years of age and older reveals that a total of 74% of respondents describe their health in the past year as “good” or “excellent,” and a majority of respondents believe in the importance of diet, exercise, and a positive attitude for maintaining optimum health (National Council on Aging, 2015). At the same time, other data indicate that the majority of older adults live with at least one chronic health condition (Administration on Aging, 2015). Whether morbidity will be diminished remains an open question about which there are differing opinions. For instance, an older person with a strong cardiovascular system but with dementia could live for many years with significant cognitive impairment, harkening to the Struldbrugs. Hopes for delaying disease by health promotion alone may not be realistic or appropriate. Moreover, a rising curve of survival into old age does nothing to alter maximum life span, the “natural death” for which the Struldbrugs longed.

Scientists have pursued basic research on the biology of aging in the hope of avoiding the Struldbrug problem—namely, having enormous numbers of frail, sick, and dependent older people whose lives are prolonged in a desperate condition. But do we really need to understand the biology of aging to address this challenge? Couldn’t we simply concentrate research attention on eliminating the big “killer diseases” that prevent people from living out a full life span? For example, if the most prevalent diseases of later life, the big killers such as stroke, heart disease, and cancer, were eliminated, wouldn’t we all live to be over 100? Unfortunately, the answer is no. Curing all these diseases would give us, on average, only a decade or so more years before some other disease would kill us.

What if we could eliminate all diseases? Would immortality then be at hand? Alas, the answer is no. Time and chance take their toll in the form of accidents. Unless we turn our attention to the underlying vulnerability of human biology, we may change life expectancy, but not maximum life span. Still worse, we might succeed in creating more and more long-living “Struldbrugs.” It is quite possible that future declines in death rates will actually have a small effect on average life expectancy, but create much larger numbers of very sick old people. The fear, then, according to critics, would be a Struldbrug scenario: an expansion of morbidity.

This trend will take place, pessimists believe, because medical technology is improving survival prospects for patients with disabling conditions associated with fatal disease—Alzheimer’s is a good example. But the basic progression of the disease remains unchanged. The length of life lived with disability for this part of the population would increase, what Olshansky and Carnes (2002) refer to as manufactured time. A second reason for the expansion of morbidity is the increasing role of nonfatal diseases of aging, such as arthritis and some forms of stroke (Olshansky et al., 1991).

But optimists take a different view. Analysis of data from the National Long Term Care Survey by Kenneth Manton and colleagues (2006) showed a significant decline in chronic disability in the older adult population between 1984 and 1989. The proportion of older adults with disabilities actually became lower in this period, reflecting improved treatments and lifestyle modifications. For instance, the number of those ages 65 and older with high blood pressure dropped from 46% in 1982 to 39% in 1989; the percentage of Americans with emphysema went down from 8.9% to 6.4%. The research team concluded that there is reason to expect further progress in the future as successive generations of older people show gains in income and education. On the negative side, they pointed to conditions requiring special
attention, such as musculoskeletal problems (e.g., arthritis) and dementia. However, more recent research on morbidity suggests that the opposite trend may be occurring: an increase in longevity and morbidity over the past two decades (Crimmins & Beltrán-Sánchez, 2010). It remains to be seen what these patterns will look like as we move farther into the 21st century, though recent research suggests that many of the major diseases that impact older adults are in decline (Kolata, 2016).

Basic research may find answers to the common diseases of old age. But beyond curing specific diseases, researchers are also looking at interventions that could delay or actually reverse the process of aging. Here, we confront far-reaching questions about the impact of research on the biology of aging. Are we talking about moving the average life expectancy closer to the upper limit of the maximum life span—say, closer to age 120? Or are we talking about pushing that upper limit itself—say, up to age 150 or 200? Or, are we concerned with enhancing to the fullest extent possible however many years one has to live? In either event, successful antiaging interventions would have large consequences for human society, and if the results from a recent survey are any indication, many Americans do not feel positively about radical life extension (Pew Research Center, 2013). Until such research yields practical results, society will have to cope with the consequences of having more long-living individuals, and one of those consequences is vulnerability to disability and disease.

**URBAN LEGENDS OF AGING**

"Prevention and health promotion are the way to save money in health care."

Sounds appealing, but it's probably not true. That's what Professor Louise Russell concluded more than two decades ago in her massive economic study, *Is Prevention Better Than Cure?* The non-partisan Congressional Budget Office in 2009 agreed, finding that health promotion measures would in fact not save money in health care reform. People might escape one disease only to die of another later on, with added costs. Prevention might be a good idea, but it won't necessarily save money.

**EPIDEMIOLOGY OF AGING**

Although aging is not in and of itself a disease, with increasing age comes increasing susceptibility to disease. The vulnerabilities of later life are the subject of *geriatrics*, or the medical specialty that focuses on aging issues. Much has been learned about the major diseases of later life, and this subject is important for debates about aging, health care, and society (Blumenthal, 1983; Gawande, 2014).

Basic to our understanding of diseases in society is the discipline of *epidemiology*, which originally acquired its name from the scientific study of epidemics. Today, epidemiology is more broadly understood as the use of statistical techniques to study the distribution of diseases in human populations. A basic goal for the epidemiology of aging is to understand what diseases are most common among older people and to assess their impact (White et al., 1986).
An example of how epidemiological data are organized is given in Exhibit 4, indicating selected chronic conditions that are the leading causes of death among older people.

**Major Diseases in Old Age**

There are characteristic diseases of old age (Blumenthal, 1983). For example, today, three quarters of all deaths among persons ages 65 and older come from just three diseases: heart disease, cancer, and stroke. Death rates for heart disease and stroke have declined in recent decades, but they still remain the leading causes of death. If heart disease were completely eliminated as a cause of death, the average life expectancy for someone 65 years old would increase by 7 years, ignoring the likelihood of death from one of the other leading causes. Although often not listed separately as a cause of death in vital statistics, Alzheimer’s disease was the fifth leading cause of death chiefly afflicting people ages 65 and older in 2007 (Centers for Disease Control and Prevention, 2011).

Along with diseases causing death, we also need to consider chronic conditions that persist for a long period, regardless of whether they cause death. Chronic illness is much more common among the old than among the young. Rates of chronic illness are 46% for those ages 65 and older, compared with only 12% for those younger than that age. Currently, 80% of adults 65 and older living in the United States have one chronic condition, and 50% have at least two (Centers for Disease Control and Prevention, 2007). Exhibit 5 shows the prevalence of selected chronic conditions for people ages 65 and older.

**Exhibit 4  Chronic Conditions That Were the Leading Causes of Death for U.S. Adults Aged 65 or Older, 2007–2009**

<table>
<thead>
<tr>
<th>Condition</th>
<th>All races/ethnicities</th>
<th>White, non-Hispanic</th>
<th>Black, non-Hispanic</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Disease</td>
<td>27.7%</td>
<td>25.6%</td>
<td>28.3%</td>
<td>23.5%</td>
</tr>
<tr>
<td>Cancer</td>
<td>22.1%</td>
<td>22.3%</td>
<td>21.9%</td>
<td>21.6%</td>
</tr>
<tr>
<td>Chronic Lower Respiratory Diseases</td>
<td>6.5%</td>
<td>5.9%</td>
<td>6.8%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Stroke</td>
<td>6.5%</td>
<td>5.9%</td>
<td>6.8%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Alzheimer's Disease</td>
<td>4.4%</td>
<td>3.0%</td>
<td>4.6%</td>
<td>5.0%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.8%</td>
<td>2.8%</td>
<td>2.9%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Influenza &amp; Pneumonia</td>
<td>2.6%</td>
<td>2.6%</td>
<td>2.6%</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

SOURCE: Figure 2 from Centers for Disease Control and Prevention (2013).
Arthritis

Arthritis is the most familiar and one of the most prevalent chronic diseases of later life; it afflicts nearly half of all persons ages 65 and older. Arthritis is basically an inflammation of the joints, also commonly known as “rheumatism,” and it is the most important cause of physical disability in the United States. Symptoms include pain and red, swollen joints and muscles. Like cancer, arthritis is actually the name of a group of as many as 100 syndromes, all slightly different. Rheumatoid arthritis can occur at any age, but osteoarthritis is distinctly related to old age and is aggravated by degeneration caused by wear and tear of the joints.

Degenerative joint disease in some variety is almost certain to occur in people over the age of 70, but the effect of such disease on ADLs varies tremendously, and most people live full and active lives with it. The cause of arthritis is not known, and there is no cure, but treatment of the disease to reduce symptoms can be effective. Painkilling drugs are not costly, but for the very serious cases, joint surgery—for example, hip replacement—can be expensive.

Osteoporosis

Osteoporosis is a condition involving the deterioration or disappearance of bone tissue leading to loss of strength and, often, to fracture. The disease is most prevalent in women (four times more common than in men), especially beyond the age of menopause, which occurs around age 51. When weakened by osteoporosis, bones are more likely to break, with serious
consequences. It is estimated that 1.5 million fractures occur each year as a result of osteoporosis. A hip fracture, often related to a fall, is one of the most common events precipitating admission to a nursing home. About half of those who survive fractures will require some form of long-term care. Data for the period 2005-2010 indicate that 16% of adults 65 and older have osteoporosis. The highest incidence rates are for women aged 65 and over, one fourth of whom have osteoporosis; an even larger percentage have low bone mass. In 2008, the total medical cost of osteoporosis and fractures was $22 billion in the United States (Looker & Frenk, 2015).

**Parkinson’s Disease**

Parkinson’s disease is a degenerative neurological disorder characterized by a loss of control over bodily movement. It afflicts about half a million people in the United States, chiefly older people. Symptoms include tremors or shaking of the head and hands, leading to progressive loss of muscle control and the ability to walk unaided. Parkinson’s disease is an age-related syndrome, and its incidence increases steadily after midlife. For reasons not clear, dementia is quite prevalent among persons with Parkinson’s, and depression is common as well. Parkinson’s appears to be caused by lack of dopamine production in brain cells, but there is no treatment that slows the progression of the disorder. Drug treatment, such as L-Dopa, however, can relieve symptoms of the disease (Pahwa & Lyons, 2013).

**Cancer**

Recent research has focused on aging and changes in the immune system of the body. The strength of the immune function begins to decline after puberty, and with advanced age comes a propensity to develop autoimmune disorders, such as arthritis, as well as higher rates of cancer. In fact, cancer is overwhelmingly a disease of old age, with half of all cancers occurring in people ages 65 and older. The incidence of malignant disease rises progressively with age, so cancer today is the second leading cause of death for Americans ages 65 and older, accounting for 22% of deaths among older people (Centers for Disease Control and Prevention, 2013).

Different forms of cancer seem related to age, but that apparent relation may be the result of longer exposure to cancer-causing chemical substances known as carcinogens (e.g., asbestos, tobacco, or alcohol; see Connor, 2016). Because of successful medical interventions, older people who have cancer are living much longer than in the past, so cancer can often become a chronic disease. A person diagnosed with slow-growing or controllable forms of cancer may live many years, thus increasing the cost of medical care over a longer period of time. But it is also possible to prolong the period of dying for those with incurable cancer, raising questions not only about the ethics of termination of treatment but also about the cost of life prolongation.

**Cardiovascular Disease**

The leading cause of death for people ages 65 and older remains cardiovascular disease, which includes stroke and heart disease. Heart disease alone accounts for nearly a third of all deaths, whereas stroke accounts for another 6.4% of those deaths (Centers for Disease Control and Prevention, 2013). In the past two decades, there has been a decline of almost
30% in deaths from heart disease, and the cardiovascular condition of older people shows wide variations. According to physiological studies, the heart of a healthy 80-year-old man performs as well as that of someone in his 20s within the normal range of everyday activities. But, unfortunately, about two thirds of men in their 70s have clear evidence of coronary heart disease, so death rates remain high. The economic cost of heart disease is staggering: more than $444 billion in 2010, according to figures from the Centers for Disease Control and Prevention (2011).

Stroke refers to a neurological deficit in the brain arising from a sudden disturbance in the blood supply. A stroke often results in some degree of paralysis, often on one side of the body, or loss of other functions, such as speech, and it can result in coma or death. Although one stroke in three leads to immediate death, another one in three causes permanent disability.

Dementia and Alzheimer’s Disease

Dementia is an organic mental disorder involving progressive loss of the capacity to think and remember. It is not characteristic of normal aging but is the result of a specific disease process. Dementia is characterized by confusion and memory impairment and may manifest itself in a wide range of symptoms, such as wandering or losing things. Dementia can have various causes, but Alzheimer’s disease is one of the major ones. Patients with Alzheimer’s may retain social skills and conceal their impairment to some degree. Alzheimer’s disease is often hard to diagnose and separate from other cognitive impairments.

Senile dementia of the Alzheimer’s type is the most common cause of irreversible dementia of old age, accounting for two thirds of all dementia conditions. But other causes can be vascular conditions, such as multi-infarct dementia, which could be described as a series of very small strokes that eventually damage the brain. The proportion of people with Alzheimer’s disease rises dramatically with each decade of age over 65, doubling every 5 years. It strikes 1 out of 12 persons older than age 65, but the figure rises to 1 out of 3 among those over age 80, at least in some community studies. Between 2 million and 4 million Americans may now be afflicted with the disease. Numbers are uncertain because of difficulties with definitive diagnosis of the disease. About half the residents of nursing homes have some form of dementia, usually Alzheimer’s.

Alzheimer’s is a disease caused by deterioration of brain cells, characterized by plaques and tangles (Borenstein & Mortimer, 2016). The disorder typically progresses through stages from mild memory loss, through significant cognitive impairment, to very serious confusion and the loss of ability to handle dressing, bathing, or other ADLs. By the end stage of the disease, there may be incontinence, loss of speech, and inability to walk. A definitive diagnosis of Alzheimer’s is difficult, and confirmation usually can be made only upon autopsy. But a mental status examination can assess functional cognitive losses produced by the disease.

Alzheimer’s disease is irreversible and generally foreseeable in its course. In advanced stages, taking care of persons with the disease living in their own homes usually becomes impossible. The result is often placement in a skilled nursing home, sometimes lasting many years. Even when a person’s quality of life has declined severely, it is feasible to use modern medical techniques to cure his or her physical illnesses, such as pneumonia or kidney failure, and thus prolong his or her life, resulting in great expense.

In terms of the health care rationing debate, acute care medical intervention can actually be less costly than long-term care over a period of many years for persons with Alzheimer’s.
Alzheimer’s appears to be one of the most common diseases of late adulthood, and genetic factors clearly contribute to cases of Alzheimer’s disease with an early onset. One indication of genetic influence is the association between Down’s syndrome and Alzheimer’s. Genes found on chromosomes 21 and 14 are known to cause early-onset Alzheimer’s, whereas another gene on chromosome 19 seems linked to late onset. The lifetime incidence among relatives of patients with Alzheimer’s is estimated at around 20%, or three to four times the risk among comparable groups. If Alzheimer’s were purely a genetic disease, however, then it would be expected that identical twins would always come down with the disease. But they do not, thus proving that environmental factors must also play a role in expression of Alzheimer’s disease. The classic “Nun Study” showed that individuals with the classic physiological markers of Alzheimer’s may not show symptoms of the disease at all (Snowden, 2002). Some neurologists, therefore, point out that it remains very difficult to separate Alzheimer’s from other processes of brain aging (Whitehouse & George, 2008).

Although Alzheimer’s disease is a major problem, its prevalence among older people should not be exaggerated. For one thing, epidemiologists have noted an unexpected, and unexplained, decline in rates of dementia, suggesting reasons for hope (Jones & Greene, 2016). This trend parallels a trend to push some chronic diseases later in advanced age. For another thing, most people ages 65 and older do not suffer from memory defects or dementia. Among all those over 65, perhaps one in five people have a mild or moderate mental impairment. This means the overwhelming majority of older people have no mental impairment at all. Memory defects are quite limited among the large majority of older people, and the capacity for learning and growth in later life remains impressive.

**Responses to the Diseases of Later Life**

Interventions to eliminate specific diseases, such as cancer and stroke, can increase life expectancy, but they do not raise the maximum life span of individuals. Furthermore, curing a life-threatening illness does not prevent other nonfatal diseases that may bring chronic disability. One of the big questions about aging, health, and society is whether our health care system is capable of dealing with a growing aging population. Many critics charge that it is not. Medicine in the United States has often neglected the dimensions of caring for and coping with people who have illnesses that cannot be cured, such as Parkinson’s and Alzheimer’s. That neglect is a matter of special concern for geriatric medicine.

The approach of clinical medicine in most advanced countries, and certainly in the United States, focuses almost entirely on discrete causes of disease and their cures. Intrinsic causes within the organism—in other words, vulnerabilities of aging—are not well understood and are not the focus of attention. The paradox here is that, because survivorship has been increasing, the aged have become an increasing proportion of society, and the remaining fatal diseases, whether cancer or Alzheimer’s, are linked to the process of aging.

Will a breakthrough in understanding the biology of aging solve this problem? There are reasons for doubt. For example, there is a whole class of age-related changes not likely to be affected by improved DNA repair, a favored mechanism for explaining biological aging.
Many physical changes of old age are in the wear-and-tear category and include the decalcification of bones, uric acid encrustation in cartilage of joints, and cholesterol accumulation in blood vessels. It might be possible for geriatric medicine to develop strategies to control causes at the tissue level and to introduce rehabilitative methods that improve the clinical picture. The problem is that many of today’s dramatic medical techniques—such as kidney transplants and bypass surgery—do nothing to affect the underlying process of aging. We can keep patients alive, but we can do little to improve their quality of life.

An overview of geriatric epidemiology gives a concrete picture of what the Struldbrug problem might look like in the future. Success in curing some forms of cancer or heart disease could raise life expectancy but leave larger numbers of people living with the burden of chronic diseases such as stroke, arthritis, and osteoporosis. A pragmatic approach to geriatric medicine might favor interventions designed to reduce the burden of age-related diseases on individuals as well as society.

Advances in medical technology and adoption of health promotion measures could bring average life expectancy closer to the theoretical upper limit of the maximum life span. But would we then be inadvertently multiplying the Struldbrug problem? Those in favor of age-based health care rationing would cut funding from expensive life-sustaining interventions for the very old and redirect those resources toward quality-of-life interventions for age-related diseases. But there are serious questions about whether paying for extended long-term care is actually cheaper than any alternative we can imagine. Those questions involve the economics of health care.
The emergence of the Struldburg scenario in the United States has had an important public consequence—namely, rising health care expenditures for the very old. In 2015, older adults comprised 14.5% of the population (Administration on Aging, 2015). In addition, each older adult consumed significantly more total health care expenditures—more than five times higher than spending per child (Centers for Medicare and Medicaid Services, 2014b). This increase has taken place against a background of escalating costs for health care in general. The proportion of the gross national product for health care today is twice what it was in 1965 when Medicare was enacted, and Medicare remains at the center of the economics of health care for aging (Medicare Payment Advisory Commission, 2004). Medicare spending has grown in the past three decades from $37 billion in 1980 to approximately $618 billion in 2014 (Centers for Medicare and Medicaid Services, 2014b).

As a nation, the United States has gone from spending approximately 9% of the gross national product on health care in 1980 to spending more than 17.5% in 2014 (Centers for Medicare and Medicaid Services, 2014b). Health care spending is growing faster than the general rate of overall inflation, and it remains a concern for the future. Concerns about cost and access were factors leading to adoption of the Affordable Care Act in 2010 (Jacobs & Skocpol, 2012). Despite some success in reducing total health care spending, costs are expected to rise as the baby boom generation moves into old age. We face the paradox that spending more on health care may be getting us less (Bradley & Taylor, 2015).

**Reimbursement Systems**

Medicare and Medicaid are the dominant government reimbursement systems for health care for older people (Cohen et al., 2015). Medicare is the chief federal government program that pays for health care; it covered 55 million people in 2015, including 46 million older adults and persons of all ages with disabilities (Kaiser Family Foundation, 2015). Medicare doesn't pay for all health care for older people. It has serious limitations: for example, it doesn't pay for the first day of hospitalization; it doesn't cover hearing aids, eyeglasses, or dental care. (See Exhibit 6 for the incidence rates of sensory impairments for older adults.) It also excludes long-term care coverage, except for limited periods after hospital discharge. However, Medicare now covers prescription drugs, as a result of the Medicare Modernization Act (MMA) of 2003. Like most insurance plans, Medicare has various levels of premiums, deductibles, and copayments that may change yearly, and Part B covers approximately 80% of physician expenses. Medicare is available primarily on the basis of age, in contrast to Medicaid, a health program funded by both the states and the federal government, which is available only to those below the poverty line. Medicaid is a major source of payment for long-term care.

Medicare was created in 1965 as part of the Social Security Act. Before Medicare, as many as half of people ages 65 and older were without health insurance, whereas today almost all people are covered. Much has changed in the Medicare population in more than three decades. Since 1965, life expectancy has risen and the 65 and older population grew from 9% to over 14% of the total U.S. population. Medicare has had a major impact on the health of the older adult population: Since 1965, half as many Americans die of heart attacks and a third as many die of strokes, and this is a tremendous accomplishment.
Like Social Security, Medicare is funded from payroll taxes on a worker’s entire income. Unlike Social Security, whose problems lie many decades into the future, Medicare faces short-term financing problems. Overall, Medicare spending has risen much faster than the cost of living, and thus it presents government policy makers with a serious problem of cost control.

Medicare actually comprises two distinct programs: Part A, or hospital insurance, and Part B, supplementary medical insurance, covering nonhospital care, which primarily includes physicians’ services along with limited home and outpatient services. Medicare Part A is financed by a compulsory payroll tax administered as part of the Social Security tax levied on all wages up to a specified limit. Part B covers 80% of doctors’ bills for Medicare beneficiaries with incomes less than $85,000 per year who paid a $104.90 monthly premium in 2015, deducted from their Social Security checks (Kaiser Family Foundation, 2015). The monthly premium for beneficiaries with incomes above that range are higher and may increase. Exhibit 7 shows where money from Medicare goes.

In 1965, when it was enacted, Medicare spent a little more than $3 billion. In 2014, it spent more than $618 billion (Centers for Medicare and Medicaid Services, 2014b). Nearly two thirds of that total goes to hospitals, where acute and often high-technology care is provided. If health care rationing on the grounds of age were ever to be introduced, it would probably take place in the Medicare program and would show up in the large sector of Medicare concentrated on hospitals.

Although Medicare expenditures have climbed dramatically, Medicare still covers only about half of the out-of-pocket medical expenses of older people: roughly the same percentage as when the Medicare program was enacted in 1965. Part of the reason is that Medicare Part B reimburses 80% of physicians’ “reasonable charges.” In fact, the amount reimbursed may or may not reflect actual charges in a specific geographic area. In practice, many physicians in the past have charged much more than the officially allowed Medicare
rate, with the patient paying the difference. But that practice has now begun to change. Since 1993, physicians participating in Medicare are limited by law to charging no more than 15% above the rate set for Medicare reimbursement. That law was passed because fewer than half of physicians were willing to accept the official Medicare reimbursement as full payment because the rate was too low. Because of limits on what Medicare will pay, around 30% of Medicare beneficiaries also have private Medigap insurance policies to cover the remainder of their medical bills.

Our experience so far with both the Medicare and Medicaid programs gives cause for concern about what might happen if cost-containment measures cut down on physician reimbursement from government insurance programs. Officials of the American Medical Association have rejected the idea of the government setting limits on the fees of doctors, and they have argued that such fee limits will inevitably bring about de facto “rationing” of health care.

Similar fears erupted after 1983, when Congress passed a law limiting payments to hospitals under Medicare. In 1983, Congress responded to the high hospital costs of Medicare Part A by introducing a prospective payment system: a new way of reimbursing hospitals...
for the cost of treating Medicare patients. Under prospective payment, hospitals receive a fixed amount for a specific diagnosis given to a patient no matter how long the hospital stay or the type of service required. Over the past decade, the new prospective payment system has held down hospital costs below what they would have been without these cost controls. But critics charge that the system has resulted in higher outpatient costs and in displacing costs onto families of patients who are discharged “quicker and sicker” (see Exhibit 8).

The system has created hundreds of diagnostic categories, or diagnosis-related groups (DRGs), that determine how much a hospital will be reimbursed for patient care. The system, in effect, gives an incentive to hospitals to keep their costs down and discharge patients as early as medically feasible. Despite protests and concerns about the new reimbursement system, DRGs have become an accepted fact of life in U.S. hospitals.

In the 1980s, it was widely feared, and sometimes charged, that these cost-containment measures would lead to “patient dumping” by hospitals, along with widespread deterioration of patient care. Such widespread deterioration did not occur, but the 1983 law did have its intended effect in holding down Medicare Part A spending from where it would have been otherwise. Cost containment for hospital spending proved effective, but during the 1980s, Medicare Part B spending for physicians tripled in size, and outpatient costs—for example, home health care spending—have increased dramatically in recent years.
In part because of the success of DRGs, Congress acted to try to control costs under Medicare Part B. In 1989, Congress passed another law revising the Medicare reimbursement formula for physicians in different medical specialties. The new legislation introduced a so-called Resource-Based Relative Value Scale in the national Medicare program. This Relative Value Scale means that primary health care providers, such as internists, geriatricians, and family practitioners, will be paid more for their services, whereas other specialists, such as some surgeons, will be paid less than they were before.

This reimbursement scheme is an effort to give more incentive to medical specialties involving prevention, health promotion, and quality of life, in contrast to the expensive technologies of life prolongation. Doctors who spend more time with patients but do not use “high-tech” procedures are to be paid more than they were paid previously. The aim of the new measures is to provide a more equitable system of payments reflecting skill, time, and intensity of work.

Despite the ongoing debate about the particulars of Medicare, it commands strong public support as a universal public insurance program for physical illness. By contrast, no consensus has been mobilized to make Medicare a universal public program for long-term care, mental health treatment, or early detection of illness, which might be beneficial in the long run. Medicare will not pay for regular physical examinations or for dental care. Older adults make use of mental health services at only about half the rate of younger people partly because of lower rates of mental illness, but also because today’s older generation is likely to be more resistant to using formal services.

Despite recent changes in Medicare, preventive care and health promotion remain low priorities. Critics of this bias note that a great deal of money is spent on acute conditions such as heart disease and cataracts. An expensive procedure such as coronary bypass surgery remains fully covered by Medicare, but a physical exam to detect hypertension or recommend preventive diet or medication is not. Medicare reflects the same priorities favored by the health care system for the nonaging population. The emphasis on technology is in some ways perplexing. Contrary to popular belief, it was not medical technology, but largely social interventions—such as improved sanitation, diet, and public health measures—that accounted for the large drop in mortality in the 20th century. Perhaps further efforts to make lifestyles healthier could help control health care expenditures for our aging population.

The federal government has subsidized some research into the health effects of lifestyle improvements (see, for example, Centers for Disease Control and Prevention, 2007). It has also subsidized research and development in medical technology; in fact, expenditures for biomedical science have increased from $3 million after World War II to approximately $17 billion in 2015 (Harris, 2015). Yet in contrast to private industry, in which investment in research and development leads to lower costs, advances in medical technology have actually led to higher costs for health care. With each new technique for life prolongation, we increase the numbers of those who are very old and very sick.

**Prospects for the Future**

The escalating cost of health care has become a major problem for older adults and for other groups in society. Currently, Medicare spending as a share of the gross domestic product is approximately 3.6 and is projected to continue to increase into the future (Kaiser Family Foundation, 2015). Will biomedical technology help solve the problem or only make it worse?
Some trends in place give cause for concern. First, in health care, new technologies can introduce new services and higher costs. Second, health care costs, even after adjusting for inflation, have continued to rise faster than inflation. Third, the aging of the U.S. population will add to these expenses because incidence of illness and disability is higher among the old. Those ages 65 and older spend about four times as much money on health care as people below that age. In terms of overall spending for health care, expenditures for those ages 65 and older, who comprise only about 14% of the total population, now amount to more than a third of all health care spending.

It is difficult to predict future levels of use of health care by an aging population. In the past, there were gross underestimates of expenses. In 1965, planners projected the cost of supplemental medical insurance under Medicare. But in 1970, only five years later, there had been a fivefold increase in the cost of that program. Between 1967 and 1975, the rate of use in both parts of Medicare had gone up from 367 per 1,000 enrollees to 528 per 1,000. Recently, Medicare has been growing at a rate three times the rate of inflation.

In light of these huge and rising costs, it is not surprising that there is widespread concern about the prospect of an aging population in the future. Based on U.S. Census Bureau middle-range population forecasts, it is estimated that the Medicare costs for the oldest-old (85+) could increase sixfold by the year 2040. In light of these trends, as we shall see, there is serious discussion about the rationing of health care in the future (Hoffman, 2012).

LONG-TERM CARE

Dramatic end-of-life decisions often attract public attention in debates about the economics of health care. But a far more widespread phenomenon is taking place away from the hospital intensive-care ward for those needing long-term care. People in need of long-term care may live in many different environments, ranging from a nursing home or assisted-living facility to a single-family residence. Whether in the community or in an institution, people with severe chronic conditions often need help with ADLs, and supportive services can be costly.

How will we provide these needed services? The problem cannot be left for the future. Growing numbers of frail, chronically ill older adults are already in need of long-term care, at home or in institutions. Instead of expecting old people to die early or hoping to find the biomedical fountain of youth, we face the practical problem of how to pay for long-term care, whether provided by families, by community-based services, or in institutions. Opinions differ about who should bear the cost of elder care.

Consider the hypothetical case of George and Martha Walton. They never expected to live into their 80s, but they’re glad to be alive and glad still to be in their own home in Middletown, USA. Maintaining their home, however, has gotten more difficult since George had his first stroke. Martha finds herself exhausted, and her arthritis prevents her from getting around the way she used to. They can’t afford to hire help to come into their home. They’ve looked into alternative housing arrangements, but the thing George fears most of all is that his condition will deteriorate and he’ll end up in a nursing home. They wonder, where will they turn next?
Housing for Older Adults

George and Martha Walton are struggling with long-term care issues regardless of whether they even use or recognize the term long-term care. George and Martha like living in their own home, and they don’t want to go into a separate residential facility. Their situation, which is typical, shows why the distinction between long-term care services and housing for the aging is not clear-cut. Housing for older adults was long conceived as a bricks-and-mortar affair; that is, it was mainly a matter of financing or subsidizing shelter dedicated to the aged. But increasingly, it is recognized that social as well as physical concerns must be taken into account in planning for housing for the aging population (Golant, 2015).

Today, around 90% of the older population in the United States lives in conventional housing, made up of mostly single-family houses or apartments. In 2014, only 3.2% of the population ages 65 and older lived in an institutional setting (Administration on Aging, 2015). Even among the oldest-old, only about a quarter of the population lives in specialized or supportive housing. But health care for an aging population inevitably brings consideration of housing needs as well.

In the early 21st century, housing of an aging U.S. population may produce greater demand for low-cost housing and coordination of services. Building affordable housing for an aging population is a challenge as funding from the federal government for senior housing continues to shrink. Community-based services, such as home health and adult day care, are likely to be important in the future as cost-containment pushes providers to look for alternatives to expensive medicalized facilities such as the nursing home.

The term nursing home can refer to any residential facility giving some degree of nursing care to older adults or people with disabilities (Johnson & Grant, 1986). In the United States, about two thirds of these facilities are proprietary, that is, operated as commercial, for-profit organizations. Most of the rest are voluntary or nonprofit, with a few run by municipal governments. Among these facilities, it is useful to identify the skilled nursing facility, which is an institution offering medical care, such as a hospital, as well as everyday personal care services to older adults or people with disabilities. An intermediate-care facility, in contrast, gives health-related care to patients needing a lower level of support. An extended-care facility offers short-term convalescent help to patients after an extended hospital stay.

At the same time, interest in new approaches to senior housing is also growing. Today, many public and private sector strategies for planned senior housing are being discussed, including a wide range of options: naturally occurring retirement communities; leisure-oriented and continuing-care retirement communities; board and care homes; adult day care and respite services; and home sharing, assisted living, and medical care in residential settings. Surveys by AARP repeatedly show that up to 90% of older people prefer to remain in their own homes: “aging in place.” In the future, we may hope to see new alternative housing arrangements and adaptations that reflect this wish (Cisneros, Dyer-Chamberlain, & Hickie, 2012).

What are the “alternative housing arrangements” that George and Martha Walton might want to consider? In the past, a home for the aged might have been an option. A home for the aged is a facility typically sponsored by a church or fraternal organization and dedicated to helping impoverished or dependent older adults. These residential facilities are less common today, but commercially developed retirement communities have been attractive to more affluent older adults (Hunt, 1983).
Also to be noted is a type of facility that has seen rapid growth: the continuing-care retirement community (CCRC) (Sherwood et al., 1997). These offer a combination of housing and health care and typically provide a level of social support for those who find it difficult to live on their own. Originally known as “life care communities,” CCRCs promise residents the opportunity to “age in place” by combining different levels of health care with housing, nutrition, social supports, and physical security. CCRCs integrate these services under a comprehensive insurance contract that may involve a form of managed care.

Some analysts believe that, at their best, CCRCs can offer a nearly ideal model of health care for older adults because of the guaranteed commitment and integrated approach to housing and long-term care needs (Somers & Spears, 1992; U.S. Government Accountability Office, 2010). But there are drawbacks. CCRCs are often expensive. George and Martha probably would not qualify. A distinguishing feature of the life care community is that residents are committed to remain there for the rest of their lives: They pay a large entry fee, which can be above $100,000, in addition to monthly maintenance fees, in return for guaranteed support as they grow older and more frail.

If CCRCs represent the high-income end of the housing continuum, it is important to note the prevalence of domiciliary care facilities and board-and-care homes at the lower end (Morgan, Eckert, & Lyon, 1995). These are homes that provide mainly custodial or personal care for older adults and people with disabilities who don’t need the intensive medical supervision of a nursing home but who do need help with ADLs.

Another approach is shown by assisted-living facilities that offer residents and their families a homelike environment with personal but limited supportive care (Zimmerman et al., 2001). The atmosphere of assisted living promotes a maximum degree of autonomy, independence, and privacy. But assisted-living complexes can also cover the entire continuum of care: from those that provide only minimal help with ADLs to those offering residents complete nursing care. Assisted living is much more attractive than a nursing home. As hospitals have been pressured to discharge patients earlier and as nursing homes have become facilities for very sick people, assisted living has grown rapidly (Golant & Hyde, 2008).

A great advantage of assisted living is that, in contrast to separate retirement communities, assisted-living providers expect to integrate themselves into a surrounding service network, including adult day care, Meals on Wheels, or other social services. Payment for assisted living today is mostly private out of pocket, but insurance and public financing seem likely to grow in the future. By 2010, approximately 735,000 persons were living in 31,000 such facilities around the United States, and it is a fast-growing industry (see Exhibit 9). Still, some questions about assisted living remain unanswered: What happens when residents begin to get sick or seriously impaired? In contrast to skilled nursing facilities, state regulation of assisted living is not consistent (Mollica, 2000).

The federal government subsidizes rental housing through the Section 202 and Section 8 housing programs for low-income older adults. But housing programs have often looked only at “bricks and mortar” and failed to take into account the social support needs of older people, which tend to increase with advancing age. Those needs are better taken into account through congregate housing: a residential facility providing nutrition, housekeeping, and supportive services for the marginally independent older adult (Chellis, Seagle, & Seagle, 1982). Along the same lines, there has been interest in shared housing, an alternative housing arrangement involving either group residence with shared common areas or a
homeowner who rents out unused rooms (Streib, Folts, & Hilker, 1984). Still another option is senior cohousing (Durrett, 2009). These options, including subsidized housing, have mostly been targeted at low-income older adults.

However, for those who can afford it, middle-class and more affluent groups will want to consider leisure-oriented retirement communities, which are different from CCRCs and other supportive living arrangements because they lack a formalized network of social support services. Residents are mostly “on their own” and are expected to live quite independently. Leisure-oriented communities have a prominent focus on recreational activities; by both image and reality, they cater to a healthy, young-old population (ages 65–74) who aim to enjoy the positive lifestyle offered by such communities.

A question for the future is whether these leisure communities can maintain their recreational identity as the population begins “aging in” and a demand for increasingly intensive support services develops (Folts & Streib, 1994). Still another question, discussed in later chapters of this book, is whether it is socially desirable for housing for older generations to be segregated from housing for younger generations. As we imagine housing options in an aging society, more attention is being given to creating “age-friendly communities” that address older adults’ multifaceted needs (Baker, 2014; Scharlach & Lehning, 2015).

All of these options are important, but they probably won’t help George and Martha Walton, who just want to remain in their own home. Much of the effort at improved housing for the aging has been planned housing initiated by either the government or the private marketplace. But the overwhelming majority of older Americans live in unplanned housing, typically in the same home and neighborhood they have lived in before, just like George and Martha.

### Chronic Care in Old Age

An explosion in demand for long-term care is found in all advanced industrialized countries as a larger and larger proportion of the population survives into old age (Feder, Komisar, & Niefeld, 2000). Compared with the general population, older people on average show twice as many days in which activities are restricted because of chronic conditions. The most important of these conditions are arthritis, rheumatism, and heart conditions. But there are sharp differences in the impact of such conditions among the population ages 65 and older. Apart from people in nursing homes, in 2012, only 10.2% of the young-old group say they need help with everyday tasks such as household chores, dressing, and going shopping. By contrast, among the oldest-old, the proportion of those needing help jumps to approximately 30% (see Exhibit 10).

#### Exhibit 9  Assisted Living by the Numbers, 2010

- Residents: 735,000
- Female: 74%
- Male: 26%
- Age distribution: 65–74: 9%; 75–84: 7%; 85+: 54%
- Help with 3 or more ADLs: 38%

Long-term care is fundamentally different from acute health care. Acute care is appropriate for conditions that result from a single cause that can be treated by medical intervention. By contrast, the chronic conditions requiring long-term care last a long time and may have varied causes. Examples of such disorders are Alzheimer’s disease and other dementias and stroke leading to permanent disability. The result is an inability to perform ADLs (Füzéki & Banzer, 2013; Katz, 1963).

What does this mean in concrete terms? Consider the case of George Walton, who has reached this point. A series of small strokes have affected him profoundly. His condition has deteriorated to the point where he needs help getting to the bathroom and even feeding himself. Martha has done the best she can, but their children, Carol and Robert, have now convinced them that the only alternative is for George to go into the local Middletown nursing home, where he can get the round-the-clock care he needs. George and Martha are afraid to do it; they don’t like the idea at all.

In light of George Walton’s deterioration, he is likely to enter a skilled nursing facility at some point. In 2014, 1.2 million older Americans lived in nursing homes, more than all those in hospitals at any one time, but still less than 3.2% of the older population (Administration on Aging, 2015). Though a small proportion of the older adult population, the size of today’s nursing home population is partly a tribute to medical technology and the success of the longevity revolution. But it may also reflect the fact that U.S. society has

**Exhibit 10** Percentage of Persons With Limitations in Activities of Daily Living by Age Group, 2009

![Graph showing percentage of persons with limitations in activities of daily living by age group, 2009.](image)

**SOURCE:** Centers for Disease Control and Prevention, 2012.
failed to provide accessible and affordable alternatives to living in a nursing home—namely, long-term care based in the home or community. A sizable number of people in nursing homes don’t need to be there and could probably live in community settings if appropriate services were available. Estimates of the proportion of the nursing home population in this situation range from 10% to as high as 40%.

Why are George and Martha so fearful about entering a nursing home? Are they right to be afraid? The nursing home has been called a total institution, a term used to describe organizations such as prisons, mental hospitals, and boarding schools—that is, facilities that treat people like “inmates” rather than as individuals (Goffman, 1961). In a nursing home, the daily regimen is carefully organized and scheduled, so residents may lose any sense of control over their environment and easily become depressed. Nursing home placement often comes after a critical life-threatening event, such as breaking a hip (Kane et al., 2013).

A lot of criticism of nursing homes finds support in careful observational studies of life in these facilities, most notably in a classic study by Gubrium (1975), and there have been other critiques of poor conditions in assisted-living facilities, which are far less regulated than skilled nursing facilities (Gaugler & Kant, 2015). Studies have shown how the poor quality of nursing homes arose out of repeated failures in public policy to guarantee good-quality long-term care. In light of these facts, it is understandable that so many older people today fear institutionalization (Baker, 2007).

Nevertheless, just like schools or hospitals, the quality of long-term care facilities varies widely. The stereotyped view that “all nursing homes are bad” does a disservice to older adults who actually need skilled nursing care, not to mention the untold numbers of devoted nursing home employees. This stereotypical view can also lead to guilt and anxiety for families who are trying to make good decisions about care for their elders. Government monitoring and regulation have meant that nursing homes today have made improvements over the past, but institutional long-term care still falls far short of what is desirable (Kane et al., 2013). Moreover, there is a common misconception that, once someone is admitted to a nursing home, residence there is inevitably a life sentence. It turns out that length of stay in nursing homes varies widely because some people stay for only a brief time. Around two thirds of nursing home stays will last fewer than three months.

How likely is it for older people to anticipate entering a nursing home? Among all people ages 65 and older, only about 5% are in nursing homes at any given time. In other words, it is a mistake to imagine that most or even many older people are in nursing homes. But this low 5% figure may understate the importance of nursing homes in the lives of the very old. It turns out that the percentage of those who will spend some time in a nursing home before they die is much larger: up to 40% of people ages 65 and older. The lower 5% figure comes from citing the percentage of people in a nursing home only at a single point in time. Note that this difference between these two figures—5% in a nursing home at a single point in time versus 40% over the course of a lifetime—shows the dramatic difference in how statistics can be presented. These two figures correspond to a cross-sectional versus a longitudinal view of nursing home residence.

The need for chronic care varies significantly among subgroups of older adults. For the young-old, the chance of entering a nursing home is small—only 1 in 100—but for the oldest-old, the chance goes up to nearly 1 in 5. Specific risk factors that increase the chances for nursing home placement include mental impairment, chronic disability, advanced age, and spending time in a hospital or another health facility.
**Functional Assessment**

A key step in determining what kind of help people need is professional long-term care assessment. This determination often serves a “gatekeeping” role in deciding what services will be provided. A *multidimensional functional assessment* takes place when a geriatric professional, such as a doctor or nurse, conducts a full examination of an older adult’s physical, mental, and social conditions. This test is more than a physical examination because it covers ADLs, as well as physical and mental health. Among the most important of these activities are feeding, toileting, transferring out of a bed or chair, dressing, and bathing (Füzéki & Banzer, 2013). A comprehensive functional assessment also looks at social and economic resources, as well as elements such as the physical environment and even strain on caregivers. All these elements play a part in determining the kind of service an older adult may need (see Exhibit 11).

Does a failing score on an assessment test mean that it’s time to enter a nursing home? Not necessarily. The key to interpreting an assessment lies in the functional emphasis—that is, asking how an impairment actually affects performance of daily tasks such as shopping, doing housework, handling personal finances, and preparing meals (Kane & Kane, 2000). A comprehensive approach to functional assessment is important because someone with, for

**Exhibit 11**: Selected Disability Indicators Among Adults Aged 18 and Over, by Sex and Age: United States, 2014

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<table>
<thead>
<tr>
<th>Age Group</th>
<th>Serious Difficulty</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Concentrating, Remembering, or Making Decisions</td>
<td>Doing Errands Alone</td>
</tr>
<tr>
<td>18–64 years</td>
<td>4.4 4.5</td>
<td>3.1 3.9</td>
</tr>
<tr>
<td>65–74 years</td>
<td>6.1 5.3</td>
<td>6.4 9.4</td>
</tr>
<tr>
<td>75–84 years</td>
<td>10.8 11.2</td>
<td>12.9 20.7</td>
</tr>
<tr>
<td>85 years and over</td>
<td>18.8 21.5</td>
<td>26.2 45.0</td>
</tr>
</tbody>
</table>

 Percent

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**SOURCE**: Figure 6 in Centers for Disease Control and Prevention (2015).
instance, mild memory impairment or limited physical mobility may be able to live quite satisfactorily alone in an apartment as long as the environment remains safe and a neighbor or relative comes by regularly to help out. For the same reason, a physical assessment looks not only at biological organ systems but also at medications being taken and the impact of sensory impairment on ADLs.

**The Continuum of Care**

A 65-year-old today can expect to live, on average, for 19.3 more years (Administration on Aging, 2015). During those years, it is likely that health status and service needs for any individual will change, so provision for long-term care will have to reflect changes over time. Why shouldn’t long-term-care services take those changes into account? The idea of a continuum of care is based on the goal of offering a range of options responsive to changing individual needs, whether from less intense to more intense, whether at home or in an institution (Brickner et al., 1987).

The ideal of a continuum of care expresses the aim of keeping older people out of nursing homes—the most expensive and service-intensive setting—as long as possible. The aim instead is to maintain people in their homes, in independent living, or in the least restrictive alternative. If we were to take seriously the ideal of a continuum of care, it would mean spending more money to enlarge the availability of community-based long-term-care services as well as options for home modification and other solutions so that older adults could age in place. Such a goal would serve the purpose of promoting maximum independence and personal control and might also help minimize public expense. The reasons for promoting a continuum of care include both choice and economics, but it is rare to find a full continuum of care in most communities in the United States. There are many gaps, and the long-term-care service system remains fragmented and confusing (Binstock, Cluff, & Mering, 1996).

Health care is important, but we should not forget the importance of social care and contact for people like George and Martha. What happens to Martha when she is left all alone after George has entered the nursing home? Who will watch out for her and her needs? If George and Martha were lucky, Middletown, USA, would have a full range of services to help them out, as a few communities already do. The kinds of formal support services delivered to the home that are shown in Exhibit 12 can play a key role in enabling frail older adults to remain in their homes as long as possible (Quinn et al., 1982). Across the entire continuum of care, one of the most exciting innovations has been “culture change” in long-term care, ranging from the Eden Alternative to the Green House Project, both inspired by geriatrician Bill Thomas (Jurkowski, 2013).

All of these formal support systems provide a degree of companionship, monitoring, and concrete services for older adults who are frail and isolated. They also can shore up the social network of family, friends, and neighbors—that is, the totality of informal helping relationships that maintain integrity and well-being. Gerontologists have documented the crucial role that these natural support systems play in providing social care and their enormous role in the lives of older adults (Antonucci, Birditt, & Akiyama, 2009; Cantor, 1980).

If George Walton had not needed round-the-clock care, there might have been alternatives for him other than going into a nursing home. For instance, why not provide some nursing services on a daytime basis while he remains at home? That, in essence, is the strategy of adult day care, which is usually offered five days a week. Clients visit a
Senior centers and congregate housing | Senior citizens’ centers offer social and recreational opportunities. Lunches provided for older adults at neighborhood sites, such as senior centers and churches.

Telephone reassurance | Usually performed by peer volunteers. Daily phone calls, typically shortly after wake-up time, to provide support and monitor status. If telephone is not answered, someone goes to the home to check on the client.

Friendly visitor | Volunteer visits, talks with, or reads to a frail homebound older adult.

Chore service or handyman | Visiting person performs outdoor tasks, such as lawn care or snow removal, for the older adult; also may make small repairs and perform minor maintenance.

Homemaker | Visiting person performs light housekeeping (cleaning, washing dishes, vacuuming, laundry, meal preparation, etc.) and food shopping. Services are performed in the home but do not include services that involve touching the client.

Meals on Wheels | Home delivery of meals supported under the Older Americans Act.

Personal care | Visiting person performs trained but not professional work for the older adult, such as bathing, dressing, and assistance with grooming. Services include touching the client but not health care services.

Home health care | Performed by a trained professional, such as a registered nurse or licensed practical nurse. Services include administration of medications, measurement of blood pressure, changing of dressings, and so on.

Mental health services | Provision of counseling, psychotherapy, and psychological support services. Practitioners may be psychiatrists, psychologists, nurses, or social workers.

Outpatient medical care | Provision of a range of services, from checkups and diagnostic monitoring through therapeutic procedures short of hospital admission.

Adult day care | Supervision of dependent older adults by professionals or paraprofessionals, offering respite to family caregivers.

Board and care | Residential placement. Meals are provided, housekeeping is performed, and medication reminders are available.

Intermediate-care nursing home | Placement in a facility with (less than 24-hour) supervision and nursing care provided.

Skilled nursing facility | Placement in a nursing home with 24-hour services provided by registered nurses.

Inpatient hospital care | Admission as an inpatient to an acute care facility.

**SOURCE:** Krain (1995).
community facility, where they are given needed medical and social services as a group during the day, and then return to their homes at the end of the day.

Another alternative is home health care, in which home care aides provide health-related tasks such as rehabilitation exercises or toileting and transferring patients who are bed-bound (Portnow, 1987). Visiting nurses who can dispense medication and perform skilled nursing functions also play a critical role. Home health services have expanded dramatically in recent years as an alternative to institutionalization and as a means of ensuring speedier discharge from hospitals.

These forms of community-based long-term care can sometimes be more cost-effective than a residential nursing home because housing costs are not involved. Most important, they offer an opportunity for those who can to remain relatively independent. The experience of other countries, such as Canada and Great Britain, suggests that adult day care, along with other varieties of community-based long-term care, will have to play a larger role in the United States than it has in the past (Kane & Kane, 1987).

**Paying for Long-Term Care: An American Dilemma**

The costs of long-term care are projected to increase rapidly and dramatically into the 21st century (see Exhibit 13). In the past 10 years, the annual growth rate for nursing home care has been more than 12%. Few individuals can afford to pay the complete cost of long-term care in a nursing home. Usually, Medicaid pays part of the bill. Future projections of

In-home health care and physical therapy services are an example of the continuum of care. The transition into an institutional setting can often be delayed by bringing appropriate services to older adults in their own homes.
long-term-care expenditures suggest that private (out-of-pocket) and Medicaid sources will continue to be the biggest source of payment for nursing homes (O’Brien & Elias, 2004).

Advocates for home or other community-based care believe that staying at home costs less than entering a nursing home, just as George and Martha want. But home care is not always cheaper than institutional care. Cost estimates for home care typically fail to include the real value of housing or the value of unpaid family caregiving. Moreover, there is sharp debate about whether we should pay family caregivers to do what is normally done by family members for one another.

The experience of Medicaid payment for nursing home care suggests that some frail older people may end up being placed in nursing homes because institutional care, not home or community-based care, is the only form of long-term care paid for under the U.S. system. When advocates for older adults propose large increases in long-term care, the question arises of who will pay for the expansion (Rivlin & Wiener, 1988).

Should families provide for their own, or should the cost of expanded long-term care be covered by government? Paying for long-term care remains an American dilemma.

**Self-Determined Death**

Our society so far has not been prepared to explicitly ration health care on the grounds of age. Nor do we seem willing to face up to the public policy problem of paying for long-term care. But at some point, decisions become unavoidable, and therefore we turn to our last
option: self-determined death. Modern biomedical technology not only enables larger numbers of people to survive into old age, but it has also forced care providers to make explicit decisions about the end of life. The result has been a continuing debate about the so-called right to die, which involves choices from forgoing life-sustaining treatment all the way to assisted suicide (Glick, 1992; Rosenfeld, 2004). In 2005, the right-to-die debate focused on the case of Terri Schiavo, and in 2015, on Brittany Maynard, both relatively young women. But in reality, the debate will increasingly be about end-of-life care for older people.

Today, this debate is taking new forms as the cost of health care rises and the oldest-old population increases in numbers. In the future, termination-of-treatment decisions may不可避免地 become intertwined with cost-containment pressures. Instead of individuals claiming a “right to die,” we may even see health care providers or policy makers suggesting that some people have a “duty to die” to stop “futile” medical treatment that uses up scarce resources.

This prospect is not just hypothetical. A case in point is the story of Helga Wanglie, who at age 86 broke her hip and was admitted to a nursing home. As a result of complications, Wanglie ended up on a respirator and suffered brain damage. The hospital staff felt that, due to her medical condition and advanced age, Wanglie should not receive further life support. Her family, however, insisted that treatment be maintained, so the case wound up in court, which agreed with the family. In many other cases, providers have taken a different view and insisted on treating patients while the family asked to end medical treatment.

Another case in which financial considerations became mixed up with termination of treatment was the case of *Grace Plaza of Great Neck, Inc. v. Elbaum* (1993). In this instance, Jean Elbaum was in a persistent vegetative state (coma) and was being kept alive by tube feeding. Elbaum had made it clear that she would not want to be kept alive under such circumstances, but the nursing home refused to honor the family’s wishes. Instead, the facility provided treatment and then sued the family for payment of care provided against their wishes. Another case in which financial considerations became mixed up with termination of treatment was *Betancourt v. Trinitas Hospital in New Jersey* (2010). Ruben Betancourt was a 73-year-old retired machinist who suffered brain damage after a surgical procedure. Doctors determined that he was in a persistent vegetative state, and Betancourt’s family sought guardianship, believing that further care was futile. By the time Betancourt died, the hospital estimated that treatment had cost up to $1.6 million. Courts could not render a decision in this case, but the case went on to become a celebrated instance in the ethical debate over cost and medical futility (Sataline, 2010).

In recent decades in the United States, discussion about the right to die has developed along legal and ethical lines focused entirely on individual rights and decisions; it has not focused on resource-allocation issues. But the Wanglie, Elbaum, and Betancourt cases, in different ways, show how end-of-life decisions may now become entangled in considerations about who will pay the bill and whether institutions should expend resources on care that is “medically futile.”

The question of medical futility will involve values and will depend on the different treatments involved. One study looked at several different kinds of treatment that might be withheld from older adults and explored the differences among them (U.S. Office of Technology Assessment, 1987). Antibiotics, respirators, cardiopulmonary resuscitation, and kidney dialysis are all different forms of medical technology. A patient’s personal decision about one kind of intervention may not hold for another kind. Similarly, a decision may be
made in one way at home and differently in a nursing home or a hospital. The setting could make a significant difference in how health care personnel act and what families can expect. Perhaps the most important new developments in the right-to-die debate will center on the question of whether the U.S. health care system can devise practices and forms of treatment that are both respectful of patients’ wishes and attentive to the uncertainties involved in end-of-life decisions.

Another question that arises is whether it is in the best interest of depressed or debilitated patients to have life-sustaining care terminated because of poor quality of life. The topic is controversial because the patient’s best interest may or may not coincide with the interest of the family or of health care providers. When subjective well-being declines and patients want to end their lives, should geriatric health care professionals treat this as a matter of self-determination or a case of suicide prevention?

Most people are uncomfortable when economic considerations become involved with end-of-life decisions. But increasing pressure for cost containment in health care may make it difficult to keep the two matters separate. In 1990, Congress passed the Patient Self-Determination Act to uphold patients’ rights. But analysts quickly noted that the law is expected to decrease costs for health care by ending unwanted care. In one recent study, advance directives specifying limits on end-of-life care were found to lower costs, at least in regions where end-of-life care spending was the highest (Nicholas et al., 2011). As financial concerns become intertwined with right-to-die considerations, we may wonder whether backdoor rationing of health care could make it more difficult for older patients to assert their rights. It is always cheaper to say no to treatment than to say yes.

Debates about costs and self-determination take place against a background of hopes and fears centered on end-of-life decisions. Our hopes are symbolized, in the poem by Oliver Wendell Holmes, by the “wonderful one-hoss shay” or carriage, which lasted 100 years and a day and then fell apart all at once, as we saw earlier in this book. Our common hope, in other words, is to live a long life and “fall apart” all at once without decay. But our fears are symbolized by the horrifying image of Swift’s Struldbrugs, mentioned earlier in this chapter, the same people who today might be wandering in dementia or hooked up to feeding tubes. For increasing numbers of older Americans, self-determined death seems a way to resolve this struggle between hope and fear at the end of life.

**Late-Life Suicide**

Self-determined death can mean many things, ranging from termination of treatment to active euthanasia or assisted suicide. Those who favor self-determination for end-of-life decisions generally assume that it is possible to make a rational decision to end one’s life (e.g., to refuse further treatment and simply permit death to occur). That, at least, is the premise involved in the court decisions that uphold the right to self-determination.

But are these decisions always rational? If they aren’t, does that fact mean that end-of-life decisions cannot be left to individual choice? The question is a difficult one. It is not possible to consider the arguments about end-of-life decisions for older people without taking into account mental health issues: specifically, depression, which is a primary cause of old-age suicide. Suicide is now one of the leading causes of death among the old. The suicide rate for the general population is 12.9 per 100,000, whereas in 2014 the suicide rate for those over age 85 was 19.3 per 100,000 (see Exhibit 14 for another view of these data).
How can we understand old-age suicide and its causes? The first great sociological investigator of suicide, Émile Durkheim, distinguished several types of suicide. He described “altruistic suicide,” or self-sacrifice for the sake of the group or society (Durkheim, 1897/1951). A soldier giving up his life on the battlefield to save comrades would be an example of such self-sacrifice. This pattern could describe the voluntary death of some older persons in preindustrial societies facing conditions of economic scarcity. The same pattern might also apply to end-of-life decisions among older people today who fear becoming a burden on their families.

Durkheim also described a form he called “anomic suicide,” derived from his sociological concept of anomie, or a condition in which individuals feel hopeless and cut off from any sense of meaning in life. This condition is relevant to thinking about the position of old age in contemporary society. Today, older people commonly experience role loss when they give up previous roles upon retirement, the death of a spouse, or the loss of other social positions. Rosow (1974) described old age in contemporary society as a role-less role—that is, a status with no clearly defined purpose or rules of behavior (see also Blau, 1981). A final type of suicide described by Durkheim is “egoistic suicide,” where an individual may not be closely integrated into wider society—for example, among the oldest-old, who have outlived most close relatives. In such cases, it might seem perfectly rational for people to end their lives.

As a general rule, the rate of suicide tends to go up with age and to hit a peak after age 65 in the United States as in other advanced industrialized countries. Estimates of suicide remain uncertain because there are 100 suicide attempts for every completed suicide. Among the older population, however, 80% who threaten suicide actually follow through. Furthermore, among older adults who are ill, there is no way to estimate those who end their lives by non-compliance with medical treatment or other forms of self-neglect.

There are pronounced differences in suicide rates among subgroups of older adults, as Exhibit 15 indicates. Among ethnic groups, Blacks have a suicide rate only about 60% of the average for Whites, and unlike Whites, the rate does not increase in old age. For all age groups, men are much more likely to commit suicide than women, and the difference between the sexes widens with advancing age. For example, according to 2007 data, the suicide rate for White men over 85 was 45.42 per 100,000, and 84% of all suicides in later life occurred among men.

Characteristic conditions preceding late-life suicides include loneliness, social isolation, diminished economic resources, presence of illness or disability, and, above all, depression. Depression is an important public health problem for older adults and must therefore be taken seriously by clinicians and others who work with older people. Early identification and treatment for depression remain a key measure for suicide prevention.

In considering depression and suicide in old age, it is important to maintain a balanced perspective. Older people, by and large, are not unhappy. In fact, most older people enjoy good mental health and a positive attitude. The United States of Aging Survey, conducted in 2015, found that 86% of those ages 60 and over reported feeling “very confident” or “somewhat confident” about maintaining a high quality of life as they grow older (National Council on Aging, 2015). Even when exposed to stress, older people often show a remarkable capacity for adaptation and resilience, for instance, in coping positively with bereavement or chronic illness in later life. Adaptation reflects the capacity of the individual to cope with environmental demands and maintain subjective well-being. But when stress exceeds
Exhibit 14  Death Rates for Suicide Among People Aged 65 and Over by Race and Sex

![Bar chart showing death rates for suicide among people aged 65 and over by race and sex.]

**SOURCE:** American Foundation for Suicide Prevention (2014).

Exhibit 15  Suicide Rates for People Ages 65 and Over, 2007

![Bar chart showing suicide rates for people ages 65 and over, 2007.]

**SOURCE:** American Association for Suicidology (2009).
the capacity for coping, psychotherapy and other mental health interventions may play an important role in maintaining the capacity of those in the last stage of life to make rational decisions about the end of life (Butler & Lewis, 2002).

End-of-life choices must also take into consideration what has been learned about the process of death and dying itself. Glaser and Strauss (1965) described the dying trajectory by which a person passes from good health to progressively worse health to the point of death. In her influential book On Death and Dying, Elisabeth Kübler-Ross (1969) developed a stage theory of dying in which the terminally ill individual moves through stages from denial to acceptance. With respect to end-of-life decisions, it seems clear that older adults who are experiencing a stage of denial or a condition of depression might make different kinds of “rational” decisions about terminating treatment. It would therefore be unwise simply to accept a patient’s “spoken choice” at face value. On the other side of the issue, clinicians might well have a less positive view of initiating aggressive medical treatment if they are aware that an older patient is in a period of terminal decline and facing imminent death.

**Conclusion**

The overall picture of aging and health care today is a mixed one. On the one hand, some optimists hope for a compression of morbidity, in which disease is postponed and good health continues until late in life. On the other hand, larger numbers of adults with physical or mental frailties are now surviving into old age. The need to make choices about treatment and life prolongation is becoming unavoidable.

The root cause of the problem is that contemporary geriatric medicine is largely symptomatic: Health care responds only after people are sick. Responding to symptoms this way is expensive and frustrating. It proceeds the same way that treatment of polio might have gone if specialists had worked to create evermore complex and refined versions of the iron lung, instead of finding a vaccine to prevent the disease in the first place. In the same way, the “iron lung” approach to geriatric care is bound to be expensive and frustrating.

The U.S. health care system, including geriatric care, spends a great deal of money on acute care conditions such as heart disease and cataracts. In that respect, Medicare simply reflects the same priorities that are favored in health care for the broader population. An expensive procedure, such as a coronary bypass operation, is fully covered by Medicare, but a physical exam to detect hypertension or recommend preventive diet change is not. Such unbalanced emphasis on technology is in some ways perplexing. Contrary to popular belief, it was not medical technology, but largely social interventions—such as sanitation, improved diet, and public health measures—that accounted for the big drop in mortality in infancy and before middle age that occurred at the beginning of the 20th century.

As a universal public insurance program for physical illness, Medicare commands strong public support. By contrast, it has not proved possible to mobilize a consensus behind a universal public program for long-term care, for mental health treatment, or for activities such as early detection that might be beneficial in the long run. Medicare will not pay for regular physical examinations or dental care. Preventive care and health promotion also remain low priorities.

Changing these priorities will be difficult, and solutions to the problems of health care and aging remain elusive. Research on the basic biology of aging will continue, and no one can
exclude a dramatic breakthrough that might reshape the conditions of health and sickness in later life. As costs continue to rise, there will be pressure for tough decisions, perhaps even for rationing (Rosoff, 2014). It is unlikely that overt age-based rationing will be adopted in the United States, but some form of “backdoor rationing” could come as a result of cost-containment efforts. It seems likely that efforts to liberalize end-of-life decisions will also continue, but we have no way of knowing how many older people or families will decide to deliberately terminate life or where such decisions may lead us as a society. Debates about aging, health care, and society are sure to continue throughout the 21st century.
To every thing there is a season, and a time to every purpose under the heaven.
A time to be born, and a time to die . . .

—Ecclesiastes 3:1–2

Americans ages 65 and older now account for more than one third of all national health care expenditures, even though they comprise only 14.5% of the population. Medicare alone spent $618 billion in 2014, though per-capita Medicare growth has begun to slow. Health care expenditures for the older population have outpaced general economic growth in recent years, even though Medicare covers only half of health care expenditures (Centers for Medicare and Medicaid Services, 2014a). Contrary to what many people assume, Medicare is not intended to cover long-term care or many chronic diseases.

As the U.S. population grows older, it seems inevitable that we must spend even more. But what are we getting for all that money? Can we really afford so much health care for an aging population, or are we heading toward a health care crisis in the 21st century, as was predicted at the end of the previous century (Wolfe, 1993)? These questions would have been unthinkable a few years ago. But today, more and more people are asking such questions. Some have even urged that we cut off expensive health care services for the very old. During the national debate over the Affordable Care Act in 2010, opponents of the new health care law charged that it would lead to “rationing,” even though there was nothing in the legislation that would support that claim (Jacobs & Skocpol, 2010). Older people, in particular, were anxious the changes in Medicare would lead to rationing of health care and “killing Grandma to pay for Pedro.”

Rationing health care on the grounds of age is troubling to most Americans. How are we to think about the justice, or the wisdom, of spending vast amounts of money prolonging the lives of the old? Prolonging life seems desirable, but it isn’t cheap. With rising costs and new advances in expensive medical technology, decisions about life prolongation are no longer questions just for medical practitioners. The decisions quickly become questions of economics and social justice: Who will get access to expensive health care resources (Hackler, 2013)?
Answers to these questions are not easy to find. Some answers that have been given are disturbing and controversial. One of the most controversial is the idea that someday, perhaps soon, we are going to have to ration health care to people above a certain age; in effect, we will be telling older people, “You’ve lived long enough.” Philosopher Daniel Callahan has proposed something akin to the sentiment of Ecclesiastes—that there is “a time to be born, and a time to die”—in short, a “natural” human life cycle that people should accept.

Callahan, in his book Setting Limits (1987), provoked enormous debate with a serious proposal to ration health care on the grounds of age. Callahan still believes in rationing by age (Callahan, 2012), and he has not been alone. Others have agreed that age can be a legitimate factor in distributing scarce resources, and some philosophers, such as Norman Daniels (2013), have also called for such age-based rationing of health care. Callahan has argued that using age as a way of limiting health care access is unavoidable, and he points to European countries, including England, Switzerland, and some Scandinavian countries, that already engage in rationing.

Callahan’s questions are basically these: How much medical progress can Americans afford, and how much money do we want to pay to keep an aging population alive longer and longer? How much should younger generations be prepared to pay for health care of the aged as a group?

**Precedents for Health Care Rationing**

It is not easy to define precisely what health care rationing is (Williams, Robinson, & Dickinson, 2011) nor to understand all the ethical dilemmas involved (Bognar & Hirose, 2014). An important question in the health care rationing debate is a practical one: Has it ever been done before? How is rationing based on age likely to be introduced in the United States? When we look at history, there is evidence that some form of rationing, whether by name or not, has been practiced in the United States for many years (Hoffman, 2012). Evidence suggests that rationing of health care resources has been occurring for quite some time in different countries around the world (Breyer, Kliemt, & Thiele, 2002; Dineen, 2011). A few examples are suggestive here.

**Denial of Kidney Dialysis in Britain**

In Britain, kidney dialysis has routinely been withheld from people above a certain age, usually 55 (Aaron & Schwartz, 2005). Doctors in Britain’s National Health Service simply don’t refer such patients to clinics that offer dialysis treatment, and the patients die. CT scans, feeding tubes, hip replacements, and cancer chemotherapy are administered at lower rates there than in the United States. In short, British health care authorities use a variety of mechanisms, including deterring people from seeking health care, delaying services, dilution of quality, and outright denial (Harrison & Hunter, 1994).

British primary care physicians have been forced to serve as gatekeepers for the system; they are responsible for denial of lifesaving care or for imposing an age cutoff. Some officials have defended the policy on the grounds that with limited resources, it makes more sense to provide funding to improve quality of life (e.g., offering ample home health care for older adults). But as the covert practice of withholding some treatment for older people became known, public defense of the practice has been abandoned (Halper, 2009).
Waiting Lines in Canada

In Canada, medical care is provided by a national health insurance system, a plan that many people believe would be beneficial in the United States. But there have been conflicting views about the Canadian system (Marmor, 1995). Under the Canadian system, virtually no one is deprived of health care because of inability to pay. For some forms of care, however, such as certain surgical procedures that are not needed to save life, it may be necessary to wait long periods. In effect, the waiting list has replaced a market system for allocating some types of medical care (Husereau et al., 2015).

Life-and-Death Decisions in Seattle

During the 1960s, when kidney dialysis first became available, there were not enough kidney machines in Seattle to take care of all the patients who could benefit from them. For a period, hospitals set up special committees to decide who would have access to dialysis. The committees wrestled with life-and-death decisions and took into account factors such as severity of illness, age, compliance with medical regimen, and social contribution. Decisions by such committees were criticized, and eventually Medicare reimbursement for kidney dialysis made it unnecessary to ration treatment.

A Rationing Plan in Oregon

The state legislature in Oregon passed legislation putting into effect a computer-based ranking of health care problems covered under the state’s Medicaid program. According to this ranking system, funding would be made available and services would be rationed not according to individual cases, but according to a consensus reached by democratic means. The state finally obtained federal government approval for the new rationing scheme, but Oregon’s proposal received approval over objections that the plan would discriminate against people with disabilities (Oberlander, Marmor, & Jacobs, 2001).

These examples show how difficult it is to get public agreement on when or how to ration scarce health care resources. Rationing policies are sometimes put into effect when a clear-cut, unavoidable scarcity exists; organ transplants are a good example. But if all that is needed is more funding, then rationing health care seems especially open to public criticism. There is evidence that Britain and other European countries have practiced age-based rationing. But virtually none has ever come out publicly and acknowledged this or defended it.

The Justification for Age-Based Rationing

Would age-based rationing be acceptable in the United States? Public opinion surveys tend to show that Americans are concerned about high costs of health care but are unlikely to attribute these costs to overuse by older adults. A majority of the American public seems willing to withhold life-prolonging medical care for critically ill older persons near the point of death, yet few people would withhold care on the basis of age alone (Hoffman, 2012; Zweibel, Cassel, & Karrison, 1993).
Some interesting light is shed on age-based rationing through an opinion survey that asked a British sample the following question: Which of two individuals should be treated if only their ages are different and it is not possible to treat both? Respondents favored treating a 5-year-old over a 70-year-old by a ratio of 84 to 1 and a 35-year-old over a 60-year-old by 14 to 1 (Lewis & Charny, 1989). In short, although rejecting proposals for age-based rationing, people tend to favor choosing younger over older patients for treatment (Kuder & Roeder, 1995; Winkelhage & Diederich, 2012).

There are a variety of ways to ration health care besides age. These include ability to pay, anticipated clinical effectiveness, waiting lists or first-come first-served, and productivity to society or social worth. In contrast to these approaches, Callahan believes that chronological age is the best criterion to use because, in his view, each of us has a “natural” life span of 80 to 85 years. When people have completed this natural life span, it is time to “move over” and give others their fair share.

There are some good reasons that can be given in favor of age-based rationing: It would be relatively efficient to administer; from a utilitarian viewpoint, older people are less productive in the economy; from an efficiency standpoint, the likelihood of benefit and years of survival derived from medical care would be less for older than for younger people. Perhaps most important, all people theoretically are members of every age group at some point over a full life course.

But there are powerful reasons against age-based rationing. One major argument against it is the fact that older adults as a group are highly heterogeneous. Chronological age by itself isn’t a good predictor of outcome for medical treatments. Once we control for confounding explanations such as disease or functional status, age largely disappears as an explanatory variable.

People on opposing sides of the political spectrum criticize age-based rationing. Those who are more conservative feel that government rationing is morally objectionable and instead favor a market approach, in which each consumer buys insurance coverage appropriate to individually defined need (e.g., medical savings accounts that work somewhat like individual retirement accounts). By contrast, those who are more liberal believe that, instead of the marketplace, we should eliminate the profit motive altogether from health care. They favor access on a more egalitarian basis, perhaps on the pattern of European welfare states or under the banner of “Medicare for all,” assuming that limits will not be set.

As we look to the future (see Exhibit 16), U.S. health care spending has risen from 16% in 2012 to 20% in 2016. Medicare currently enrolls just under 15% of the U.S. population, but this figure is expected to rise to 20% by 2025 and even higher after that (see Exhibits 17 and 18). Of all factors, mortality rates have the most powerful influence on Medicare’s future because the death rate determines the number of people who survive to become eligible for Medicare and expenditures depend on how long they will live. Would delaying the age of eligibility save Medicare? Apparently not. Even if we raised the age of eligibility from 65 up to 70—a dramatic increase—this change would save less than 15% of total Medicare costs. If Medicare faces financial problems, more far-reaching changes may have to be considered ( McKusick, 1999).

Others look to strategies such as means testing, using income-related premiums, and seeking alternative sources of revenue beyond the payroll tax for Medicare. Finally, there are those, such as economist Uwe Reinhardt, who believe that some form of rationing is required to improve the efficiency of the system but do not necessarily favor age-based rationing.
Still another strategy is “backdoor rationing,” in which implicit or indirect methods limit access to the health care system, often due to disparities in access to health care (Dilworth-Anderson, Pierre, & Hilliard, 2012; Kapp, 2002). For example, when reimbursement rules...
Exhibit 17  Number of Medicare Beneficiaries, 1970–2030

SOURCE: Centers for Medicare and Medicaid Services, Office of the Actuary.

Exhibit 18  Medicare Beneficiaries as a Share of U.S. Population, 1970–2030

SOURCE: Social Security Administration, Office of the Actuary.
such as diagnosis-related groups require a patient to leave the hospital for home care, backdoor rationing may be involved. Faced with reimbursement limits, staff members carry out screening procedures that can lead to denial of services. These “gatekeeping” practices have become a familiar part of the practice of hospital discharge planning and case management in geriatric health care. In fact, efficiency and cost control have been motives for adopting case management in many localities (Capitman, 1988).

**RATIONING AS A COST-SAVING PLAN**

One problem with age-based rationing is knowing just how much money it would save. Most of the money spent on health care for older people doesn’t go for “high-tech” care in a hospital setting. A substantial share goes for prescription drugs, nursing home care, and home health services. The cost of these last two categories—long-term care for the aged—is increasing rapidly as more and more people survive to advanced ages. Callahan favors spending more on long-term care instead of high-technology medicine.

But the rapid rise in health care costs is not chiefly the result of longevity. Several other forces are also responsible: increases in intensity of services; rate of utilization; introduction of new medical technologies; rise in real wages of health care personnel; general price inflation; and fraud, waste, and abuse, including futile medical treatment. Various strategies have been proposed to contain costs. The most common approach has been managed care as a means of combining insurance with health care providers and facilities in a unified network to control costs. During the 1990s, managed care did have a real impact in containing health care costs, although it was unpopular. But will any of these methods enable us to pay for the health care costs of an aging society? Pessimists believe that controlling costs by eliminating unnecessary care, as managed care tries to do, provides only temporary relief because we have already gotten most of the cost savings from managed care. In the long run, population aging and technological innovation may make rationing unavoidable (Schwartz, 1987).

Technology is a major driving force behind the long-term rise in health care spending. Along with medical technology come expensive treatments for life-threatening diseases such as AIDS, heart disease, and cancer. Singling out aging alone seems to miss this larger picture. Even if aggressive, high-cost interventions for older patients likely to die within a year were eliminated, the impact on total U.S. health expenditures would be negligible.

Others have questioned Callahan’s assumption that high-technology care for older adults is inappropriate or wasteful. For instance, coronary artery bypass grafting and angioplasty offer important benefits to older heart patients. Some studies show that older patients can emerge healthy from an intensive hospital stay, proving that age alone is not a good predictor of long-term survival or quality of life among critically ill older patients (Burke, 1993).

Still others have replied to Callahan’s proposal by insisting that rationing of health care isn’t necessary in the first place (Relman, 1990). They point out that the current health care system is riddled with waste and inefficiency. For example, by comparing statistics with other countries, some analysts have argued that up to half of all the cardiac bypass operations in the United States may not be needed. A study by the federal government’s General Accounting Office (1991) found that the present health care system permits unscrupulous providers of services to defraud insurance companies at a staggering rate. Current data suggest that health care fraud in the United States totals many billions of dollars per year.
No doubt medical expenses do rise toward the end of life, but costs vary dramatically among people ages 65 and older. For example, it turns out that Medicare spends up to 25% of its money on people who are most ill. Are we confronting the principle of diminishing returns? Throughout industrialized countries, health care spending increases with age, and it accelerates at advanced ages, especially for the oldest-old (85+) (Sheiner, 2009). Yet Callahan is not in favor of cutting off care for people who live in nursing homes, although the annual cost might run up to $50,000 or more per person.

Behind Callahan’s argument is a common stereotypical image of frail older patients subjected to high-technology procedures before being allowed to die. Callahan is concerned that prolonging the lives of these patients is wasteful if the same resources could be used to improve the quality of life of other old people or people of other ages. Over-treatment does occur, of course, partly because of reimbursement incentives and a humanly understandable desire to “do everything possible.” However, aggressive treatment of older adults seems to decrease as the level of impairment rises. Those with poor quality of life—for example, late-stage dementia patients—are not treated as aggressively as others. A study of heart patients over the age of 75 found that these older patients were more than 12 times less likely to receive therapy to dissolve blood clots and 8 times less likely to undergo coronary diagnostic procedures compared with patients under 65 years of age (Rosenthal & Fortinsky, 1994). In summary, frail, totally impaired patients seldom receive expensive, high-technology care; instead, they receive supportive care.

Callahan’s proposal for age-based rationing assumes that care for older patients in their last year of life is expensive because of high-technology, life-sustaining medical treatment. But the proportional cost for Medicare beneficiaries in their last month of life remained unchanged between 1976 and 1988, suggesting that expensive high-technology care was not being administered to growing numbers of dying older patients. However, more recent data suggest that Medicare expenditures for the last year of life have been increasing steadily since the late 1990s (National Association for Home Care and Hospice, 2016). This trend seems to support Callahan’s argument, but it turns out that patients who are near death are not the biggest cause of large Medicare payments. Instead, the high-cost beneficiaries tended to be survivors. Medicare expenditures for people who died actually decreased with advancing age. These facts suggest that it may be difficult to develop a policy limiting expenditures for people in the last year of life without also curtailing health care for sick Medicare beneficiaries who have the potential to survive (Garber, MaCurdy, & McClellan, 1998).

Perhaps by voluntarily avoiding unneeded care or treatment that prolongs dying, we could avoid rationing health care. The problem here, however, is that it is not so easy to predict how long a given patient will live or what constitutes “unneeded care.” Medical costs in the last year of life amount to approximately 18% of total lifetime medical costs and nearly 30% of the entire Medicare budget. The proportion has remained unchanged for the past two decades, despite innovations in medical technology (Hogan et al., 2013). The trouble is that we only know that we’ve spent money on the “last year of life” when that life is over—that is, in retrospect. Clinical studies of medical care at the end of life confirm what doctors have admitted for a long time: Medical science lacks any realistic way of determining who would have died if they hadn’t gotten the care they received. In a careful study of Medicare expenditures, among the 1% of beneficiaries who had the highest costs, a majority survived, and of the 5% with the highest costs, nearly two thirds survived. Those in favor of rationing health care on the grounds of age cannot claim any special new power of prediction.
There are many myths about the cost of care in the last year of life (Alliance for Aging Research, 1997). One study of the last year of life found that older adults who received expensive, high-technology care were those patients with good functional status at ages 65 to 79. By contrast, frail patients with poor functional status tended to receive mainly supportive care in their final year. In other words, despite the difficulty of predicting when death will occur and despite the lack of explicit rationing criteria, it may be that high-cost medical services are already being provided to the older people with age and functional status being taken into account. Moreover, high technology is not the only factor responsible for high expenses. The frail and debilitated older-old are likely to have high expenses even without high-technology care. In short, the biggest factor in high costs at the end of life may not be inappropriate high technology after all. The real solution, some critics argue, is a system of national health care combined with careful cost controls to ensure that appropriate care, but not overtreatment, is provided to people at all levels throughout the health care system, not simply in the last year of life. A variety of proposals for providing more health care in a cost-effective manner have been put into practice in recent years. These include new forms of managed care, popular with private industry, and case management, practiced by community-based health service programs. Both are methods for deciding how much care to provide individuals based on some verified assessment of individual need.

**URBAN LEGENDS OF AGING**

“Health care costs are high because we spend most of the money on old people in the last year of life.”

This one can be dubbed “The Last Year of Life Fallacy” because it confuses treatment for severe illness with unreasonable extension of life for people who are dying. Actually, it’s not easy to know when “the last year of life” will turn out to be. When we look at the data in retrospect, we see that Medicare spends around 25% of its money on people who are the sickest, that is, in “the last year of life.” It’s just another illustration of the familiar 20-80 rule: 20% of your customers account for 80% of your revenues. Of course there are cases when dying people are unreasonably kept alive, just as there are many cases of undertreatment. But we only know “the last year of life” in retrospect. For comparative purposes, in 2011 the National Institute for Health Care Management Foundation found that 5% of the U.S. population accounted for nearly half of all health care expenditures—another “discovery” that those who are sickest end up costing the most. Contrary to stereotype, after the age of 80, the use of expensive intensive care actually declines.

**THE IMPELUS FOR RATIONING**

Will more efficient management of health care distribution solve the problems of access and allocation in an aging society? The answer we give involves some forecast about the health status and needs of the aging population in decades to come (e.g., what is the likely impact of health promotion, such as reductions in smoking, or the probability of a breakthrough in understanding the biology of aging or the causes of specific diseases?).

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A prime factor in the rationing debate is economics, which can be defined as the “science of scarcity.” It is only when scarcity is at hand, when the wolf is at the door, that rationing is seriously considered. In times past, some societies have deprived older people of resources, sometimes even life itself, to make way for the young. One example often cited is the Aleut (Eskimo) tribes who at the point of starvation were sometimes forced to put an older adult out on an ice floe to die in order to have enough food for the remainder of the group. Similarly, in Leningrad during World War II, hundreds of thousands of people, including the very old, died of starvation so that young children might survive.

These life-threatening conditions that prompted rationing have become rare as economic conditions have improved. Today, we face a different kind of scarcity created by the fact that medical technology can save and extend the lives of the very sick and old. Even when the technology is cheap, caring for older people with chronic diseases such as stroke or Alzheimer’s disease can be very expensive. As new medical technologies enable us to prolong the lives of the chronically ill, the expense continues to rise.

Exhibit 19 shows a large actual and projected increase in the population ages 85 years and older. This group of people, sometimes called the “oldest-old,” also has the greatest number of health problems and costs the most in terms of health care. If expensive health care resources were rationed on the grounds of age, as Callahan proposes, then this group would probably be the group denied care.

**Cost Versus Age**

As medical technology advances, Callahan fears that life-extending technology will run up against the law of diminishing returns. We end up spending more and more to achieve limited incremental gains, often with poor quality of life, while other social needs go unmet. But is this assumption about the cost of technology correct? Some life-extending technology, such as a penicillin shot, is actually quite inexpensive. However, keeping a patient alive
and cared for in a low-technology environment such as a nursing home can be very expensive: $50,000 or $60,000 a year or more. If we really want to cut down on the expense created by the increase in the older population, why wouldn’t we also withhold inexpensive life-extending technologies? As long as we look exclusively at the economic aspect of health and aging, it is difficult to avoid thinking of choices in terms of cost-benefit or cost-effectiveness standards (Avorn, 1984). But once we adopt those standards, don’t we tend to downgrade the value of life in old age? Callahan believes that society owes older adults a decent minimum of health care, at least up to a certain age.

The high cost of more health care for the old is part of the problem. But cost alone is not the whole story for Callahan because he would accept paying for certain expensive procedures for younger people. The basic principle that Callahan wants us to consider is chronological age. In the end, Callahan, along with the verse from the Book of Ecclesiastes cited at the opening of this chapter, believes that human life has a natural rhythm or cycle, a time to live and a time to die. Callahan argues that this “natural” life span comprising the traditional 70 years and then 10 years, or maybe a bit more, should be the basis for thinking about the goals of health care. He believes we should do what we can to enable people to live out a full life span, however defined, but nothing more. After that, we should not expend scarce resources on the very old. Instead, we should let them die.

Pushing this argument further, some have even urged a “duty to die cheaply.” If preserving a life of diminished quality in old age is less of a benefit to the aged patient than the resources saved for others, then it would be in the mutual self-interest of all to have death come more quickly. This idea of solidarity and altruism makes sense in some situations, but not in others. For instance, rationing within the British National Health Service is more easily justified than in the United States because Britain operates a closed system, providing universal access to care under a regionally centralized budget. Denial of treatment for one patient means money is available to treat other patients.

Callahan’s goal might be seen as fair and even idealistic. He wants to guarantee older people, along with everyone else, access to universal health care and help everyone avoid an early, premature death. He proposes to reform the health care system by achieving a better balance of caring and curing, specifically by improving long-term care and home care. Only after accomplishing these goals, he insists, would it be time to introduce an age-based cutoff of life-extending technologies under Medicare (Callahan, 1994).

However, critics of Callahan argue that age-based rationing affects only those who depend on government-run health programs—that is, older people who can’t afford private care. Thus, proposals for rationing health care amount to a rationale for spending less for the neediest in society—in no way a just solution. Age-based rationing would tend to perpetuate or make worse the problem of access according to ability to pay.

But Callahan and others who favor age-based rationing reply that invisible forms of rationing already take place for the millions of Americans who lack health insurance. They believe that adopting an explicit rationing policy would force everyone to face up to the allocation decisions already in effect, but kept invisible. The result of this honesty would be greater fairness for all (Callahan, 2014). Indeed, Oregon’s rationing plan for Medicaid was put into effect with this idea in mind. But it seems clear that talking about rationing in any way produced more heat than light. There was confusion about exactly what rationing might mean (Leonard, 2013; Meirick, 2013). It seems clear that the controversy about rationing and allocation of health care resources in an aging society will be with us for some time to come (Binstock, 2012).
URBAN LEGENDS OF AGING

“The 2010 health care law introduced ‘death panels’ and rationing of Medicare.”

It seems that a third of Americans believe this. But there’s nothing remotely like this in the Affordable Care Act that was passed. Earlier in the legislative process, a Georgia Republican did introduce a provision permitting payment for Medicare patients to talk with their doctor about end-of-life choices, but it was stricken after controversy. The health care law did not cut Medicare, but it did slow the growth of future Medicare spending, thereby extending the life of the Medicare Trust Fund from 7 to 19 years.

GLOBAL PERSPECTIVE

Age-Based Rationing of Health Care in Britain

In their landmark book *The Painful Prescription* (1984), Henry Aaron and William Schwartz describe how age-based rationing operated in Great Britain. Compared to the United States, they found much lower rates for coronary artery surgery, X-ray exams, CT scans, kidney dialysis, hip replacement, and cancer chemotherapy. Has the situation changed in the years since then?

There are many forms of rationing, ranging from outright denial of service to long waiting lines that also limit use of resources. Waiting periods can be particularly critical. The leading British paper *The Guardian* has reported that, with prodding from the National Health Service, emergency rooms in the United Kingdom are trying to meet a new four-hour waiting time goal for emergency room care by the traditional British practice of “queuing” or lining up. Longer waiting times could present particular challenges for very old patients.

Other forms of age-based rationing are more explicit. For example, women over the age of 50 may be regularly encouraged to undergo breast screening, but invitations stop at age 70. A 2006 article in the *British Medical Journal* documented age-based rationing of care for cancer services, coronary care units, prevention of vascular disease, mental health services, and management of minor strokes. Another study by the British advocacy group Age Concern disclosed that half of family doctors said they would worry if an older family member were in a National Health Service facility. In that study, many physicians reported that they knew well that age-based rationing of treatment occurs. Sally Greengross, chief of Age Concern, said “the survey provides solid evidence that age-based rationing is the scourge of today’s National Health Service.” Even official groups can come down in favor of age-based rationing. For example, the British National Institute for Health and Clinical Excellence in 2005 examined issues of rationing related to cost-effectiveness. They concluded that there were no grounds for withholding resources based on gender or sexual orientation, or for self-inflicted conditions, such as smoking or obesity. However, the recommendations concluded that where age is an indicator of benefit or risk, age discrimination is appropriate. The debate will go on.

In recent years, debate about health care rationing has taken a new turn. There is less explicit talk about rationing, not because we have passed beyond the need for tough decisions and not because health policy experts have reached agreement about the topic. Instead, authorities have avoided using the word *rationing* (Ubel, 1999, 2015). They have adopted other terms, such as *parsimony, comparative effectiveness, or disinvestment* (Rooshenas et al., 2015). Part of this shift in language has come about because the word *rationing* has proven to be an emotional flashpoint, as we saw during debates around the Affordable Care Act when opponents (falsely) accused the law of creating “death panels” to impose health care rationing. As a result of that debate, it became impossible to include voluntary counseling about end-of-life choices under Medicare, although such counseling became an option later on. It seems to be a reality that all health care systems make decisions about allocating resources (Maynard, 2013), but they are not always transparent about it in the way that Daniel Callahan has called for.

A variety of other approaches to rationing have been put forward by health economists and others concerned with improving the efficiency of the health care system (Jones & Higgs, 1992). One approach is to limit medical procedures based on effectiveness as measured by health outcomes research. For example, angioplasty, an otherwise useful procedure, does not produce any medical benefit when performed on a person already experiencing an acute heart attack. Many procedures of doubtful benefit are employed with the Medicare population. A study by the Commonwealth Fund estimated that more than a third of all procedures reimbursed under Medicare were performed for equivocal or inappropriate reasons. Some procedures are used because doctors are familiar with them and reimbursement is available regardless of whether they are inappropriate.

Other approaches to rationing include *cost-benefit analysis*, in which we ask how much a treatment costs in comparison with the total benefit that will be created if the patient lives. For example, we might measure the patient’s future economic productivity. Obviously, a cost-benefit approach would discourage high-cost treatments for older people. Still another approach is known as *cost-effectiveness analysis* (Muennig, 2007). Here we look at which treatment provides the desired outcome for the least cost. But again, depending on the outcome measure used, the lives of the young may be favored over the lives of people who are older (Welch, 1991).

One interesting approach in health care economics is known as *quality-adjusted life years (QALYs)*. The idea behind QALYs is the commonsense view that 10 years of life with disability may not have the same value as 10 years of good health (Nord, 1999); people with more disabilities have a poorer quality of life. If functional assessment determines that some people have poor QALYs, then they should be denied health care. But who decides what counts as “quality of life”? Economists use exercises in which a patient’s own priorities and preferences are used to construct an index for comparative purposes. Then different forms of treatment with alternative outcomes can be ranked according to cost. But again, QALYs may result in resources being channeled away from the old or chronically ill—perhaps a form of ageism or discrimination against older people (Tsuchiya, 2000). All these different approaches to the economics of rationing raise a deep and difficult question: What is a human life worth (Dranove, 2003)?
Euthanasia and Assisted Suicide

Callahan is against deliberately killing people or having doctors collaborate with patients who want help in ending their lives. His rationing proposal calls for holding back treatment, not directly killing people, say, by an injection. But other critics have wondered whether Callahan’s argument isn’t inherently self-contradictory. Why is it acceptable to hold back treatment when that holding back will predictably result in a patient’s death, but it is unacceptable to cooperate with a patient who voluntarily asks for help in ending life?

It seems as if Callahan is calling for involuntary death for people above a fixed age, but at the same time, he wants to prohibit acts, such as voluntary euthanasia or assisted suicide, that people might adopt as a matter of personal choice. Is it possible that his own proposal could make more headway if he also supported voluntary withdrawal of treatment for people of advanced age (Battin, 1987)? What about the proposal by Ezekiel Emanuel (2014), who has advocated that people might voluntary set a limit on their lives of age 75? If we moved to a voluntary system, rather than the involuntary one urged by Callahan, what might be the likely consequences for society? For health professionals such as doctors and nurses? For older people?

The Debate Over Age-Based Rationing

The questions continue, and the debate goes on. Callahan himself has repeatedly maintained his original call for age-based rationing, but he has gone further in calling for wider reform of health care. He makes it clear that, in his view, health care for older adults must be rationed, but we will have to make other difficult choices to have a just system for all. Whether he is right remains the subject of vigorous debate.

In the readings that follow, we see this debate unfold along different lines. Peter Ubel, like Callahan, takes a hard line and insists that it is time to introduce explicit health care rationing, although not necessarily on the grounds of age. In contrast, Nat Hentoff, in his article, vigorously criticizes Callahan and asks what kind of society we would become if Callahan’s proposal were adopted. Howard Brody suggests that there is a highly consequential shift occurring in the United States from a debate about the ethics of rationing to a debate about the ethics of avoiding waste in the health care system.

Finally, Daniel Perry and Robert Butler argue for investment in biomedical research to ensure that old age is not an extended period of expensive frailty, but a time of health and vitality.

Daniel Callahan is serious about his proposal, and this fact has shocked many people. Critics have responded to his proposals by calling them ageist, discriminatory, and dangerous. Callahan denies that he is urging age discrimination. Instead, he wants to guarantee older people, along with everyone else, access to universal health care and thereby help everyone maximize vitality and avoid a premature death. To accomplish this goal, he believes, means we need to achieve a better balance between caring and curing in our health care system. As a practical matter, he wants a trade-off between improving long-term care and cutting off life-extending technologies to be paid for under Medicare. Setting an age limit is tragic, but it is the best we can do, Callahan believes.
Is Daniel Callahan cruel and hard-hearted, or is he instead courageous and farsighted in his willingness to advocate a controversial idea? His own words, and the response of his critics, must be the basis for what the fair-minded reader will conclude.

**FOCUS ON PRACTICE**

**Managed Care**

An important feature of health care for older people today is the spread of managed care, such as Medicare health maintenance organizations (HMOs). By 2009, 11 million Medicare beneficiaries—or 24% of the Medicare-eligible population—were enrolled in managed care plans (Research Data Assistance Center, 2011). To qualify for Medicare reimbursement, these managed care plans must provide all the services that Medicare covers; as a result, they have proved attractive to many older people. A growing minority of older Americans are using managed care (Kongstvedt, 2004). Managed care is already the dominant pattern in health care delivery in the United States. Today, a majority of HMOs offer some type of Medicare managed care plan.

There are both advantages and disadvantages for an individual to change from conventional Medicare fee-for-service to a managed care plan or Medicare HMO. On the positive side, managed care demands less paperwork. Doctors’ visits, hospital bills, and lab tests are covered in full, with low copayments and without high deductibles. Medicare HMOs may also offer extra benefits, such as low-cost prescription drugs or vision care. They also eliminate the need for private Medigap insurance, which is widespread in the Medicare population. Above all, the whole concept of “managed” care is intended to improve coordination of care and services. Finally, managed plans have a clear incentive to offer preventive health care, such as checkups and immunizations. All of these are positive points in favor of managed care.

On the negative side, managed care has the drawback of imposing limits. When people sign up, they must go through the Medicare HMO network to receive their health care. Patients can’t choose their own doctors, hospitals, or other service providers. For older people, it may prove a hardship not to be able to continue using a doctor they've known for many years. For those who travel, the plan may limit coverage when outside the service area. Above all, the managed care plan will only pay for preapproved services.

Medicare beneficiaries have long had the option of switching from traditional fee-for-service coverage to HMOs. Since the mid-1990s, managed care providers have been successful in enrolling Medicare beneficiaries in large numbers (see Exhibit 20). Since 1999, the program then known as Medicare Plus Choice allowed beneficiaries to choose from eight standardized health plan categories, including HMOs, fee-for-service plans, and provider-sponsored organizations. Managed care plans remain attractive because they offer no deductibles, extremely low copayments, and almost no paperwork or claim forms. In many instances, they provide eye and ear exams or low-cost prescription drugs.

Enrollment in Medicare HMOs remains voluntary. The young-old who are healthy today may find managed care plans attractive, but their attitudes could change later, especially if they are denied coverage or if they face a limited choice of doctors. In the new environment of managed care

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care, physician–patient relationships are likely to take on importance for older adults because their expectations about medical encounters have developed over a lifetime under the traditional fee-for-service approach. Older consumers will have to educate themselves to evaluate health-marketing appeals and become capable of choosing the most appropriate managed care provider for themselves.

There is an ongoing debate about whether encouraging more older Americans to enroll in managed care organizations will reduce Medicare costs (Gold, 2003). Some critics fear that managed care is just a means of backdoor rationing. Yet surveys suggest that older patients enrolled in Medicare HMOs may be more satisfied with their coverage than those enrolled in traditional fee-for-service plans (Margolis, 1995).

Yet the issue of hidden or backdoor rationing persists because of reimbursement under managed care. Under a complex formula, the federal government pays a Medicare managed care plan a fixed sum of money on a per-person rather than a per-service basis. This reimbursement method is known more broadly as capitation (per head). What this means is that, after receiving a fixed amount under capitation, a managed care plan then becomes responsible for each beneficiary’s full health care costs. If a person stays healthy, the managed care group gets to keep the extra money. But if someone gets sick, even if treatment costs $100,000, the plan is responsible for covering the cost, just as with any insurance plan. The profit motive, then, may introduce incentives for backdoor rationing in unexpected ways.

For example, Medicare managed care plans are motivated to avoid signing up those likely to incur large medical costs. This form of backdoor rationing can be accomplished indirectly by marketing techniques. But refusing to enroll frail older people is against federal law. Furthermore, even people who sign up while healthy are likely to get sick later on. Another approach is to cut costs by denying coverage to those who are very sick. Backdoor rationing may take the form of refusing treatments on the grounds of “medical necessity.” If a treatment fails that test, it doesn’t qualify for coverage.

What happens if someone in a Medicare HMO is denied coverage? Studies by the Government Accountability Office have found that few people appeal a denial of coverage. An appeal can take up to six months, and that is a significant time factor for someone who is 70 or 80 years old. Another federal study reported that a quarter of Medicare HMO members weren’t even aware that they had the right to appeal a denial of coverage. When beneficiaries do appeal, they sometimes win, but many decide not to go through the process. Nor does the appeals process deal with the question of quality assurance. What happens if backdoor rationing takes the form of substandard care for millions of older adults? One problem here is that quality of care is not easy to measure. A managed care organization might save money by getting patients out of the hospital earlier, but patients might then face serious problems because they ended up at home or in facilities that could not provide appropriate rehabilitation. In that case, the result could be readmission to the hospital. The Affordable Care Act (2010) made possible a response to this problem by penalizing hospitals that readmit patients within 30 days after discharge. There is evidence that this policy has given hospitals an incentive for more careful discharge (Joynt & Jha, 2013).

Denial of coverage can take place in many different kinds of services. In rehabilitative services, for example, Medicare requires “steady and meaningful improvement.” Medicare HMOs
may be inclined to interpret that requirement in stringent terms. A patient who fails to make
sufficient progress gets no more rehabilitation. In a class action suit against the federal govern-
ment, Grijalva v. Shalala (1996), attorneys for a Medicare HMO patient claimed that the health
plan repeatedly provided less coverage for a whole group of conditions and procedures, ranging
from pneumonia to hip replacement. Some managed care companies have pulled out of
Medicare altogether, citing inadequate Medicare payment increases. However, the 2003

(Continued)
Medicare Modernization Act contains provisions suggesting that the Medicare Advantage version of managed care could now be more attractive for health care consumers.

The controversy over age-based rationing has shifted to new terrain with debates about how far companies can go in limiting health care services because of the bottom line. The ultimate threat is for managed care companies simply to drop Medicare coverage. Ethical principles—justice, rights, the greatest good for the greatest number—may not be easy to apply in these circumstances. Backdoor rationing under managed care presents a confusing picture. Or should we even speak about rationing when managed care groups control access through indirect requirements that create delays and appeals without any clear resolution? As a larger number of older people sign up for Medicare managed care plans, the public debate about gatekeeping will continue.
In October 1986 Dr. Thomas Starzl of Presbyterian University Hospital in Pittsburgh successfully transplanted a liver into a seventy-six-year-old woman, thereby extending to the elderly patient one of the most technologically sophisticated and expensive kinds of medical treatment available (the typical cost of such an operation is more than $200,000). Not long after that, Congress brought organ transplants under Medicare coverage, thus guaranteeing an even greater range of this form of lifesaving care for older age groups.

That is, on its face, the kind of medical progress we usually hail: a triumph of medical technology and a newfound benefit provided by an established health-care program. But at the same time those events were taking place, a government campaign for cost containment was under way, with a special focus on Medicare. It is not hard to understand why.

In 1980 people over age sixty-five—11 percent of the population—accounted for 29 percent of the total American health-care expenditures of $219.4 billion. By 1986 the elderly accounted for 31 percent of the total expenditures of $450 billion. Annual Medicare costs are projected to rise from $75 billion in 1986 to $114 billion by the year 2000, and that is in current, not inflated, dollars.

Yet there is another powerful reality to consider that moves in a different direction: Medicare and Medicaid are grossly inadequate in meeting the real and full needs of the elderly. The system fails most notably in providing decent long-term care and home care. Members of minority groups, and single or widowed women, are particularly disadvantaged. How will it be possible, then, to provide the growing number of elderly with even present levels of care, and also rid the system of its inadequacies and inequities, and yet at the same time add expensive new technologies?

The straight answer is that it will be impossible to do all those things and, worse still, it may be harmful even to try. The economic burdens that combination would impose on younger age groups, and the skewing of national social priorities too heavily toward health care, would themselves be good reasons to hesitate.

BEYOND ECONOMICS: 
WHAT IS GOOD FOR THE ELDERLY?

My concern, however, extends beyond the crisis in health-care costs. “I want to lay the foundation for a more austere thesis: that even with relatively ample resources, there will be better ways in the future to spend our money than on indefinitely extending the life of the elderly. That is neither a wise social goal nor one that the aged themselves should want, however compellingly it will attract them. . . . Our affluence and refusal to accept limits have led and allowed us to evade some deeper truths about the living of a good life and the place of aging and death in that life” (SL, 53, 116).

The coming economic crisis provides a much-needed opportunity to ask some fundamental questions. Just what is it that we want medicine to do for us as we age? Other cultures have believed that aging should be accepted and that it should be in part a time of preparation for death. Our culture seems increasingly to dispute that view, preferring instead, it often seems, to think of aging as hardly more than another disease, to be fought and rejected. Why does our culture have such difficulty with this question?

Let me start by saying that “the place of the elderly in a good society is a communal, not only an individual, question. It goes unexplored in a culture that does not easily speak the language of community and mutual responsibility. The demands of our interest-group political life constitute another obstacle. . . . It is most at home using the language of individual rights as part of its campaigns, and can rarely afford the luxury of publicly recognizing the competing needs of other groups. Yet the greatest obstacle may be our almost utter inability to find a meaningful place in public discourse for suffering and decline in life. They are recognized only as enemies to be fought: with science, with social programs, and with a supreme optimism that with sufficient energy and imagination they can be overcome. We have created a way of life that can only leave serious questions of limits, finitude, the proper ends of human life, of evil and suffering, in the realm of the private self or of religion; they are thus treated as incorrigibly subjective or merely pietistic” (SL, 220).

In its long-standing ambition to forestall death, medicine has reached its last frontier in the care of the aged. Of course children and young adults still die of maladies that are open to potential cure, but the highest proportion of the dying (70 percent) are over sixty-five. If death is ever to be humbled, that is where endless work remains to be done. This defiant battle against death and decline is not limited to medicine. Our culture has worked hard to redefine old age as a time of liberation, but not decline, a time of travel, of new ventures in education and self-discovery, of the ever-accessible tennis court or golf course, and of delightfully periodic but thankfully brief visits from well-behaved grandchildren. That is, to be sure, an idealized picture, but it arouses hopes that spur medicine to wage an aggressive war against the infirmities of old age.

As we have seen, the costs of such a war would be prohibitive. No matter how much is spent, the ultimate problem will still remain: People will grow old and die. Worse still, by pretending that old age can be turned into a kind of endless middle age, we rob it of any meaning.

THE MEANING AND SIGNIFICANCE OF OLD AGE

There are various sources of meaning and significance available for the aged, but it is the elderly’s particular obligation to the future that I believe is essential. “Not only is it the most neglected perspective on the elderly, but it is the most pertinent as we try to understand the problem of their health care. The young—children and young adults—most justly and appropriately spend their time preparing for future roles and developing a self pertinent to them. The mature adult has the responsibility to procreate and rear the next generation and to manage the present
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Earlier generations accepted the idea that there was a “natural life span”—the biblical norm of threescore and ten captures that notion. It is an idea well worth reconsidering and would provide us with a meaningful and realizable goal. Modern medicine and biology have insinuated the belief that the average life span is not a natural fact at all, but instead one that is strictly dependent on the state of medical knowledge and skill. And there is much to that belief as a statistical fact: Average life expectancy continues to increase, with no end in sight.

There are, moreover, other strong obstacles to the development of a notion of a “natural life span.” This notion “requires a number of conditions we seem reluctant to agree to: (1) that life has relatively fixed stages—a notion rejected on the ground that we are free to make of our different stages of chronological age whatever we want; biology presents no unalterable philosophical and moral constraints or any clear pointers; (2) that death may present an ‘absolute limit’ to life—an idea repudiated because of the ability of medicine to constantly push back the boundary line between life and death; life is an open-ended possibility, not a closed circle; (3) that old age is of necessity marked by decline and thus requires a unique set of meanings to take account of that fact—a viewpoint that must be rejected as part of the political struggle against ageism, which would make of the old a deviant, marginal, and burdensome group; and (4) that ‘our civilization’ would be better off if it shared some common view of ‘the whole of life’—rejected as a politically hazardous notion, more congenial to authoritarian and collectivist cultures than to those marked by moral and religious pluralism and individualism” (SL, 40–41).

I want to argue that we can have and must have a notion of a “natural life span” that is based on some deeper understanding of human needs and possibilities, not on the state of medical technology. I offer a definition of the “natural

**A “Natural Life Span” and a “Tolerable Death”**

society. What can the elderly most appropriately do? It should be the special role of the elderly to be the moral conservators of that which has been and the most active proponents of that which will be after they are no longer here. Their indispensable role as conservators is what generates what I believe ought to be the primary aspiration of the old, which is to serve the young and the future. Just as they were once the heirs of a society built by others, who passed on to them what they needed to know to keep going, so are they likewise obliged to do the same for those who will follow them.

“Only the old—who alone have seen in their long lives first a future on the horizon and then its actual arrival—can know what it means to go from past through present to future. That is valuable and unique knowledge. If the young are to flourish, then the old should step aside in an active way, working until the very end to do what they can to leave behind them a world hopeful for the young and worthy of bequest. The acceptance of their aging and death will be the principal stimulus to doing this. It is this seemingly paradoxical combination of withdrawal to prepare for death and an active, helpful leave-taking oriented toward the young which provides the possibility for meaning and significance in a contemporary context. Meaning is provided because there is a purpose in that kind of aging, combining an identity for the self with the serving of a critical function in the lives of others—that of linking the past, present, and future—something which, even if they are unaware of it, they cannot do without. Significance is provided because society, in recognizing and encouraging the aged in their duties toward the young, gives them a clear and important role, one that both is necessary for the common good and that only they can play” (SL, 43).

It is important to underscore that while the elderly have an obligation to serve the young, the young and society have a duty to assist the elderly. Before any limits are imposed, policies and programs must be in place to help the elderly live out a “natural life span,” and beyond that to provide the means to relieve suffering.

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life span” as “one in which life’s possibilities have on the whole been achieved and after which death may be understood as a sad, but nonetheless relatively acceptable event.

“Each part of that definition requires some explanation. What do I mean when I say that ‘one’s life possibilities have on the whole been accomplished’? I mean something very simple: that most of those opportunities which life affords people will have been achieved by that point. Life affords us a number of opportunities. These include work, love, the procreating and raising of a family, life with others, the pursuit of moral and other ideals, the experience of beauty, travel, and knowledge, among others. By old age—and here I mean even by the age of 65—most of us will have had a chance to experience those goods, and will certainly experience them by our late 70s or early 80s. It is not that life will cease, after those ages, to offer us some new opportunities; we might do something we have never done but always sought to do. Nor is it that life will necessarily cease to offer us opportunities to continue experiencing its earlier benefits. Ordinarily it will not. But what we have accomplished by old age is the having of the opportunities themselves, and to some relatively full degree. Many people, sadly, fail to have all the opportunities they might have: they may never have found love, may not have had the income to travel, may not have gained much knowledge through lack of education, and so on. More old age is not likely to make up for those deficiencies, however; the pattern of such lives, including their deprivations, is not likely to change significantly in old age, much less open up radically new opportunities hitherto missing” (SL, 66–67).

A longer life does not guarantee a better life. No matter how long medicine enables people to live, death at any time—at age 90 or 100 or 110—would frustrate some possibility, some as-yet-unrealized goal. The easily preventable death of a young child is an outrage. Death from an incurable disease of someone in the prime of young adulthood is a tragedy. But death at an old age, after a long and full life, is simply sad, a part of life itself, what I would call a “tolerable death.”

This notion of a “tolerable death” helps illumine the concept of a “natural life span,” and together these two notions set the foundation for an appropriate goal for medicine in its approach to aging. “My definition of a ‘tolerable death’ is this: the individual event of death at that stage in a life span when (a) one’s life possibilities have on the whole been accomplished; (b) one’s moral obligations to those for whom one has had responsibility have been discharged; and (c) one’s death will not seem to others an offense to sense or sensibility, or tempt others to despair and rage at the finitude of human existence. Note the most obvious feature of this definition: it is a biographical, not a biological, definition” (SL, 66).

THE PRINCIPLES AND PRIORITIES OF A PLAN

How might we devise a plan to limit the costs of health care for the aged under public entitlement programs that is fair, humane, and sensitive to their special requirements and dignity? Let me suggest three principles to undergird a quest for limits:

1. Government has a duty, based on our collective social obligations, to help people live out a natural life span, but not actively to help extend life medically beyond that point. By life-extending treatment, I will mean any medical intervention, technology, procedure, or medication whose ordinary effect is to forestall the moment of death, whether or not the treatment affects the underlying life-threatening disease or biological process.

2. Government is obliged to develop, employ, and pay for only that kind and degree of life-extending technology necessary for medicine to achieve and serve the end of a
natural life span; the question is not whether a technology is available that can save a life, but whether there is an obligation to use the technology.

“That is the need for an antidote to the major cause of a mistaken moral emphasis in the care of the elderly and a likely source of growing high costs of their care in the years ahead. That cause is constant innovation in high-technology medicine relentlessly applied to life-extending care of the elderly. It is a blessing that too often turns into a curse. ... No technology should be developed or applied to the elderly that does not promise great and inexpensive improvement in the quality of their lives, no matter how promising for life extension. Incremental gains, achieved at high cost, should be considered unacceptable. Forthright government declarations that Medicare reimbursement will not be available for technologies that do not achieve a high, very high, standard of efficacy would discourage development of marginally beneficial items” (SL, 142, 143).

“The second element is a need to focus on those subgroups of the elderly—particularly women, the poor, and minorities—who have as yet not been well served, for whom a strong claim can be entered for more help from the young and society more generally. ... The elderly (both poor and middle-class) can have no decent sense of security unless there is a full reform of the system of health care. It may well be that reforms of the sweeping kind implied in these widely voiced criticisms could more than consume in the short run any savings generated by inhibitions of the kind I am proposing in the development and use of medical technology. But they would address a problem that technological development does nothing to meet. They would also reassure the old that there will be a floor of security under their old age and that ill health will not ruin them financially, destroy their freedom, or leave them dependent upon their children (to the detriment of both)” (SL, 142, 147).

“The third is a set of high-priority health and welfare needs—nursing and long-term care, prevention—which would have to be met in pursuit of the goals I have proposed. ... Beyond avoiding a premature death, what do the elderly need from medicine to complete their lives in an acceptable way? They need to be as independent as possible, freed from excess worry about the financial or familial burdens of ill health, and physically and emotionally positioned to seek whatever meaning and significance can be found in old age. Medicine can only try to maintain the health which facilitates that latter quest, not guarantee its success. That facilitation is enhanced by physical mobility, mental alertness, and emotional stability. Chronic illness, pain, and suffering are all major impediments and of course appropriate targets for medical research and improved health-care delivery. Major research priorities should be those chronic illnesses which so burden the later years and which have accompanied the increase in longevity” (SL, 142, 149).

**Euthanasia and Assisted Suicide**

Some might view my position as an endorsement of euthanasia and assisted suicide. My position “is exactly the opposite: a sanctioning of mercy killing and assisted suicide for the
elderly would offer them little practical help and would serve as a threatening symbol of devaluation of old age. . . Were euthanasia and assisted suicide to be legalized, would there be a large and hitherto restrained group of elderly eager to take advantage of the new opportunity? There is no evidence to suggest that there would be, in either this country or in any other. But even if there might be some, what larger significance might the elderly in general draw from the new situation? It would be perfectly plausible for them to interpret it as the granting of a new freedom. It would be no less plausible for them to interpret it as a societal concession to the view that old age can have no meaning and significance if accompanied by decline, pain, and despair. It would be to come close to saying officially that old age can be empty and pointless and that society must give up on elderly people. For the young it could convey the message that pain is not to be endured, that community cannot be found for many of the old, and that a life not marked by good health, by hope and vitality, is not a life worth living. . . .

“What do we as a society want to say about the elderly and their lives? If one believes that the old should not be rejected, that old age is worthy of respect, that the old have as valid a social place as any other age group, and that the old are as diverse in their temperaments and outlooks as any other age group, an endorsement of a special need for euthanasia for the old seems to belie all those commitments. It would be a way of legitimizing the view that old age is a special time of lost hopes, empty futures, and personal pointlessness. Alternatively, if it is believed that old age can have a special value, that it can—with the right cultural, economic, and political support—be a time of meaning and significance, then one will not embrace euthanasia as a special solution for the problem of old age, either for the aged as individuals or for the aged as a group. It would convey precisely the wrong symbolism. To sanction euthanasia as a special benefit for the aged would signal a direct contradiction to an effort to give meaning and significance to old age” (SL, 194, 196, 197). We as a society should instead guarantee elderly persons greater control over their own dying—and particularly an enforceable right to refuse aggressive life-extending treatment.

**Conclusion**

The system I propose would not immediately bring down the cost of care of the elderly; it would add cost. But it would set in place the beginning of a new understanding of old age, one that would admit of eventual stabilization and limits. The elderly will not be served by a belief that only a lack of resources, better financing mechanisms, or political power stands between them and the limitations of their bodies. The good of younger age groups will not be served by inspiring in them a desire to live to an old age that maintains the vitality of youth indefinitely, as if old age were nothing but a sign that medicine has failed its mission. The future of our society will not be served by allowing expenditures on health care for the elderly to escalate endlessly and uncontrollably, fueled by the false altruistic belief that anything less is to deny the elderly their dignity. Nor will it be aided by the pervasive kind of self-serving argument that urges the young to support such a crusade because they will eventually benefit from it.

We require instead an understanding of the process of aging and death that looks to our obligation to the young and to the future, that recognizes the necessity of limits and the acceptance of decline and death, and that values the old for their age and not for their continuing youthful vitality. In the name of accepting the elderly and repudiating discrimination against them, we have succeeded mainly in pretending that with enough will and money the unpleasant part of old age can be abolished. In the name of medical progress we have carried out a relentless war against
death and decline, failing to ask in any probing way if that will give us a better society for all.

“There is little danger that the views I advance here will elicit such instant acclaim (or any acclaim, for that matter) that the present generation of the elderly will feel much of their effect. That could take two or three decades if there is any merit in what I say, and what I am looking for is not any quick change but the beginning of a long-term discussion, one that will perhaps lead people to change their think-

ing, and most important, their expectations, about old age and death” (SL, 10).

**Note**


**READING 17**

**Pricing Life**

Why It’s Time for Health Care Rationing

Peter Ubel

In the United States, people frequently debate the pros and cons of managed care organizations and whether medicine should be a for-profit business. They almost never debate health care rationing. Instead, they mention it only to accuse managed care organizations or for-profit insurance companies of some egregious crime against humanity. Clearly, there are many important issues to debate about managed care organizations and about the rampant corporatization of American health care. But these debates miss the larger issue of the need to ration health care.

Managed care organizations did not create health care rationing. Instead, the need to ration created managed care. In the United States, managed care organizations proliferated largely because of their presumed ability to contain costs. But governments in Europe, Asia, and other parts of North America are also desperate to control health care costs. Outside the United States, the need to ration health care forced governments to devise other ways besides managed care to contain costs. In Canada, patients wait for months for heart bypass surgery, only to be bumped to the back of the line when another patient becomes urgently ill (Naylor, 1991). Indeed, even in the United States, managed care organizations are not the only groups engaged in rationing. Traditional fee-for-service insurance companies hire hordes of utilization reviewers to have patients discharged from the hospital earlier. State governments change eligibility criteria for Medicaid. Hospitals close down trauma centers to avoid uninsured patients. Rationing is ubiquitous. Managed care is not.

Of course, it is easier for people to argue about greedy managed care organizations, evil insurance companies, and incompetent government
bureaucrats than to discuss the need to ration health care. After all, everyone agrees that managed care organizations exist. No one agrees whether rationing exists or has to exist. Instead, too many people concerned about health care cost containment, rationing is an unjustifiable evil. It is wrong that it exists. It is immoral that physicians are allowing it to occur. It is even more evil that physicians are often the ones doing the rationing.

Given the relatively recent push to contain health care costs, it should be no surprise that the “R” word is controversial, or that it is often used to discredit political opponents or industry competitors. “Rationing” has become a code word for immoral, inappropriate, or greedy.

Because it is so unpopular, most debates focus more on whether we should ration health care than on how we should do it. In many cases the debaters do not even agree on what it means.

I want to convince people that rationing is necessary. I expect this view will be unpopular. But I am not running for public office, so the only people I have to be popular with are my wife (who is blindly in love with me) and the members of my tenure review board (who won’t read this book). I can afford to be unpopular.

We cannot have it all. We cannot afford to give every health service to every person who could possibly benefit. Most people’s health would improve if they had dietitians review what they ate for dinner and physical therapists work the kinks out of their lower backs. Most hospitalized patients and most nursing home residents would benefit from a higher nurse-to-patient ratio. If we could really afford to have it all, standard contrast dyes would no longer be standard, and newer, more expensive dyes would be offered to everyone. Instead, we would only concern ourselves with effectiveness analyses—showing us what works best so we could make sure everyone gets it. But there are limits to what we can offer everyone, and we must start figuring out how to set those limits.

In traveling farther down this road of gloom and doom, I am not only going to insist that we have to ration health care, but also that some of this rationing ought to be done by physicians at the bedside, and that our most useful rationing tool (at the bedside and at policy levels) is cost-effectiveness analysis. Although there are ethical problems with physicians rationing...bedside rationing, based on cost-effectiveness, ought to play a larger role.

The moral questions raised by cost-effectiveness analysis deserve to be debated by a broad audience.

REFERENCE


READING 18

The Pied Piper Returns for the Old Folks

Nat Hentoff

I expect that the sardonic Dean of Dublin’s Saint Patrick’s Cathedral, Jonathan Swift, would appreciate Daniel Callahan’s Setting Limits—though not in the way he would be supposed to.

Swift, you will recall, at a time of terrible poverty and hunger in Ireland, wrote *A Modest Proposal*. Rather than having the children of the poor continue to be such a burden to their parents and their nation, why not persuade the poor to raise their children to be slaughtered at the right, succulent time and sold to the rich as delicacies for dining?

What could be more humane? The children would be spared a life of poverty, their parents would be saved from starvation, and the overall economy of Ireland would be in better shape.

So, I thought, Callahan, wanting to dramatize the parlous and poignent state of America’s elderly, has created his modern version of *A Modest Proposal*.

I was wrong. He’s not jiving... Callahan sees “a natural life span” as being ready to say goodbye in one’s late seventies or early eighties. He hasn’t fixed on an exact age yet. Don’t lose your birth certificate.

If people persist in living beyond the time that Callahan, if not God, has allotted them, the government will move in. Congress will require that anybody past that age must be denied Medicare payments for such procedures as certain forms of open heart surgery, certain extended stays in an intensive care unit, and who knows what else.

Moreover, as an index of how human the spirit of *Setting Limits* is, if an old person is diagnosed as being in a chronic vegetative state (some physicians screw up this diagnosis), the Callahan plan mandates that the feeding tube be denied or removed. (No one is certain whether someone actually in a persistent vegetative state can feel what’s going on while being starved to death. If there is a sensation, there is no more horrible way to die.)

What about the elderly who don’t have to depend on Medicare? Millions of the poor and middle class have no other choice than to go to the government, but there are some old folks with money. They, of course, do not have to pay any attention to Daniel Callahan at all. Like the well-to-do from time immemorial, they will get any degree of medical care they want.

So, *Setting Limits* is class-biased in the most fundamental way. People without resources in need of certain kinds of care will die sooner than old folks who do not have to depend on the government and Daniel Callahan...

Callahan reveals that once we start going down the slippery slope of utilitarianism, we slide by—faster and faster—a lot of old-timey ethical norms. Like the declaration of the Catholic bishops of America that medical care is “indispensable to the protection of human dignity.” The bishops didn’t say that dignity is only for people who can afford it. They know that if you’re 84, and only Medicare can pay your bills but says it won’t pay for treatment that will extend your life, then your “human dignity” is shot to hell...

It must be pointed out that Daniel Callahan does not expect or intend his design for natural dying to be implemented soon. First of all, the public will have to be brought around. But that shouldn’t be too difficult in the long run. I am aware of few organized protests against the court decisions in a number of states that feeding tubes can be removed from patients—many of them elderly—who are not terminally ill and are not in intractable pain. And some of these people may not be in a persistently vegetative state. (For instance, Nancy Ellen Jobes in New Jersey.)

So, the way the Zeitgeist is going, I think public opinion could eventually be won over to Callahan’s modest proposal. But he has another reason to want to wait. He doesn’t want his vision of “setting limits” to go into effect until society has assured the elderly access to decent long-term home care or nursing home care as well as better coverage for drugs, eyeglasses, and the like.

Even if all that were to happen, there still would be profound ethical and constitutional problems. What kind of society will we have become if we tuck in the elderly in nursing homes and then refuse them medical treatment that would prolong their lives?
And what of the physicians who will find it abhorrent to limit the care they give solely on the basis of age? As a presumably penitent former Nazi doctor said, “Either one is a doctor or one is not.”

On the other hand, if the Callahan plan is not to begin for a while, new kinds of doctors can be trained who will take a utilitarian rather than a Hippocratic oath. (“I will never forget that my dedication is to the society as a whole rather to any individual patient.”) Already, I have been told by a physician who heads a large teaching institution that a growing number of doctors are spending less time and attention on the elderly. There are similar reports from other such places.

Meanwhile, nobody I’ve read or heard on the Callahan proposal has mentioned the Fourteenth Amendment and its insistence that all of us must have “equal protection of the laws.” What Callahan aims to do is take an entire class of people—on the basis only of their age—and deny them medical care that might prolong their lives. This is not quite Dred Scott, but even though the elderly are not yet at the level of close constitutional scrutiny given by the Supreme Court to Blacks, other minorities, and women, the old can’t be pushed into the grave just like that, can they?

Or can they? Some of the more influential luminaries in the nation—Joe Califano, George Will, and a fleet of bioethicists, among them—have heralded Setting Limits as the way to go. Will you be ready?

Bioethics has long approached cost containment under the heading of “allocation of scarce resources.” Having thus named the nail, bioethics has whacked away at it with the theoretical hammer of distributive justice. But in the United States, ethical debate is now shifting from rationing to the avoidance of waste. This little-noticed shift has important policy implications.

Whereas the “R word” is a proverbial third rail in politics, ethicists rush in where politicians fear to tread. The ethics of rationing begins with two considerations. First, rationing occurs simply because resources are finite and someone must decide who gets what. Second, rationing is therefore inevitable; if we avoid explicit rationing, we will resort to implicit and perhaps unfair rationing methods.

The main ethical objection to rationing is that physicians owe an absolute duty of fidelity to each individual patient, regardless of cost. This objection fails, however, because when resources are exhausted, the patients who are deprived of care are real people and not statistics. Physicians collectively owe loyalty to those patients too. The ethical argument about rationing then shifts to the question of the fairest means for allocating scarce resources—whether through the use of a quasi-objective measure such as quality-adjusted life-years or through a procedural approach such as increased democratic engagement of the community.¹

Ethicists arguing for fair rationing have had to contend with claims that the cost problem would

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be solved if we eliminated waste, fraud, and abuse. They have replied with statistics suggesting that waste, defined as the cost of deliberate fraud, accounts for less than 10% of health care costs. Moreover, eliminating all waste would result in one-time savings; the primary drivers of cost escalation—technological advances and the aging of the population—would proceed unchecked.

The facts that have recently overtaken this ethical discussion show that waste in U.S. health care, defined more broadly as spending on interventions that do not benefit patients, actually amounts to a much larger sum—at least 30% of the budget—and that this waste is a major driver of cost increases.

A case study for the shift in ethical focus is the treatment of advanced, metastatic breast cancer with high-dose chemotherapy followed by autologous bone marrow transplantation. This treatment was initially thought to offer perhaps a 10% chance of a significant extension of life for patients who would otherwise be fated to die very soon. Insurers’ refusal to pay the high costs of this last-chance treatment did much to torpedo public trust in managed care during the 1990s. Data now suggest that the actual chance of meaningful benefit from this treatment is zero and that the only effect of the treatment was to make patients’ remaining months of life miserable. In this case, the ethical debate over rationing was misplaced.

As in the breast-cancer case, waste in health care goes far beyond deliberate fraud. We have for too long ignored how much money is spent in the United States on diagnostic tests and treatments that offer no measurable benefit. Redirecting even a fraction of that wasted money could expand coverage for useful therapy to all Americans, while reducing the rate of overall cost increases.

The ethical question therefore shifts to waste avoidance. Even though the concept of medical futility has had a vexed history, this new ethical question is a subcategory of the futility debate. We used to think that the issue of futility arose only when physicians, in keeping with their professional integrity, refused to offer useless treatment even when patients or families demanded it. We now realize that futile interventions may be administered not solely because of patients’ demands but also by physicians acting out of habit or financial self-interest or on the basis of flawed evidence. The ethics of waste avoidance is thus in part a component of the ethics of professionalism.

The two principal ethical arguments for waste avoidance are first, that we should not deprive any patient of useful medical services, even if they’re expensive, so long as money is being wasted on useless interventions, and second, that useless tests and treatments cause harm. Treatments that won’t help patients can cause complications. Diagnostic tests that won’t help patients produce false positive results that in turn lead to more tests and complications. Primum non nocere becomes the strongest argument for eliminating nonbeneficial medicine.

Since elimination of wasteful, nonbeneficial interventions is ethically mandated (as has recently been emphasized in the Choosing Wisely campaign led by the American Board of Internal Medicine Foundation), the question then shifts to implementation. Here, I believe, we must consider the limitations of evidence. Data from randomized clinical trials represent population averages that may apply poorly to any individual patient. An ethical system for eliminating waste will include a robust appeals process. Physicians, as loyal patient advocates, must invoke the process when (according to their best clinical judgment) a particular patient would benefit from an intervention even if the average patient won’t. Few tests and treatments are futile across the board; most help a few patients and become wasteful when applied beyond that population. But the boundary between wise and wasteful application will often be fuzzy.

Berwick and Hackbarth note a relatively minor ethical point, but a serious policy concern: a substantial reduction in health care spending would seriously disrupt a $2.5 trillion industry, and thus the U.S. economy as a whole, and would
require careful planning and gradual implementation. A stepwise strategy also makes good ethical sense in the face of the current limitations of evidence-based medicine. Given our patient-advocacy duties, it is better first to eliminate interventions for which we have the most solid and indisputable evidence of a lack of benefit. We can then extend the policy gradually as comparative-effectiveness research identifies other sources of waste with reasonable confidence.

In the end, the ethics of rationing and of waste avoidance are complementary, not competing. Perhaps at present, waste avoidance could save enough money to permit both universal coverage and future cost control. As medical technology advances, especially with personalized genomic medicine, we will almost certainly arrive at the day when we cannot afford all potentially beneficial therapies for everyone. The ethical challenge of rationing care will have to be faced sooner or later, particularly when we confront inequitable distribution of health care resources globally.

An ethical mandate to prioritize waste avoidance doesn’t address the political hurdles, of course. Given that one person’s health care expense is another person’s income, we can anticipate pitched battles, accompanied by demagoguery such as talk of “death panels.” Medicine’s role in this campaign will pose a serious challenge to physician professionalism. Will U.S. physicians rise to the occasion, committing ourselves to protecting our patients from harm while ensuring affordable care for the near future?

**Notes**


**READING 20**

**Aim Not Just for Longer Life, but Expanded “Health Span”**

Daniel Perry and Robert Butler

Most Americans instinctively recoil at the thought that their government would try to save money by pulling the plug on life-sustaining care when it is needed by older people. In this case, their instincts are correct.

To determine a person’s access to medical care solely on the basis of that person’s age is clearly unfair, unworkable, and unnecessary. It is wrong to blame the elderly for rising hospital expenses and physicians’ fees that are driven...
principally by other factors or to require older Americans to pay for the failure of government and industry to find a more humane and workable policy to curb health care costs.

President Reagan signed into law the most sweeping Medicare expansion in that program’s 22-year history, indicating the nation’s strong commitment to providing health care to the elderly. The new catastrophic care program will cost about $31 billion over five years. Even that amount will seem small when compared to proposals for insuring Americans against the costs of long-term care, the next major health care issue to face Congress and the Bush presidency.

As the curtain rose on Congressional debate over long-term care, some came forward to argue that the United States could save billions by simply denying lifesaving medical interventions to people over a certain age—say 65 to 75. But there is a better way to control costs of providing health care to the elderly: work to eliminate the very afflictions of old age, which are costing billions in health care, long-term care, and lost productivity.

By attacking diseases associated with aging—such as Alzheimer’s disease, stroke, osteoporosis, arthritis, and others—the need for many costly medical procedures, lengthy hospital stays, and financially draining long-term care could be ended or reduced.

Why not start with a real commitment to scientific research that could extend the healthful middle years of life and compress the decline of aging into a very short time? Why not redirect federal research efforts to aim for scientific and medical discoveries to reduce frailty, improve health status, and increase independence in older people? It’s a far better goal—and more realistic—than rationing medical treatment.

At present, however, aging research is not where the U.S. government is placing its biggest bets. Most people don’t believe much can be done to change aging. Therefore, research funds generally go elsewhere.

There is every reason to fear spiraling health costs if effective ways to lengthen healthy years and delay the onset of debilitating age are not found before the baby boomers become the biggest Medicare generation in history.

Americans already are paying billions because medical science lacks the ability to cure, prevent, or postpone many chronic maladies associated with aging. And national investment in research to avoid these costs is minuscule when compared to the billions spent for treatment.

Of the $167 billion a year spent on health care for people ages 65 and older, far less than one half of 1 percent of that amount is reinvested in research that could lead to lower health care costs for chronic diseases and disabilities. That is a poor investment strategy for a nation soon to experience the largest senior boom in history.

Tinkering with changes in the health care delivery system can save some money, but these savings will not equal the long-term benefits of dramatic medical and scientific changes that alter the way people experience old age.

If scientists do not find a way to treat Alzheimer’s, for instance, by the middle of the next century, there will be five times as many victims of this disease as there are now simply because of the demographic shift that is occurring. Incontinence, memory loss, and immobility are the main factors driving long-term care and high health costs to the elderly. If no advances occur in these and other conditions of aging, up to 6 million older Americans will be living in nursing homes, instead of the 1 million who are there today.

Unfortunately, there may be no way to prevent aging per se. However, there are conditions that occur only as a person ages. Many of these can be prevented. The risk of suffering a chronic disease such as arthritis or osteoporosis is very slight at middle age. But from the forties onward, that risk doubles exponentially about every five years until someone in the mid-eighties has about a one-in-three chance of having dementia, immobility, incontinence or other age-related disabilities.
If medicine could delay the beginning of decline by as few as five years, many conditions and the costs they incur could be cut in half. The ability to re-set biological clocks to forestall some of the decline of aging may be closer than anyone realizes, thanks to new knowledge in immunology and in the molecular genetics of aging.

Answers may be near. Help for immobility, osteoporosis, and incontinence can be achieved with only a modest extension of present technologies. If the U.S. doubles its present meager $30 million for osteoporosis research, by the year 2010 this condition could be eliminated as a major public health problem, which now affects 90 percent of all women over 75.

Learning how to postpone aging could help lower health care costs and improve the health of older Americans at the same time. The goal here is not just longer life span but extended “health span,” with fewer problems caused by chronic disease.

Questions for Writing, Reflection, and Debate

1. Is Callahan right in his suggestion that our modern U.S. culture thinks of aging as “hardly more than another disease”? Does it make sense to talk about aging as a “disease,” the cause of which might be identified and then perhaps even “cured”? How do we decide whether something is a disease? Following Callahan’s own argument, would it be a good idea to promote antiaging research if this might reduce the expenses of geriatric care?

2. Antibiotic therapies such as erythromycin today are inexpensive. According to Callahan’s own argument, would they have to be withheld from the very old just because they are “life-extending”? Or is it only expensive therapies that should be withheld? What happens if a cheap therapy helps people to survive an illness, but then it turns out to be expensive to take care of them?

3. How do we know when rationing starts taking place? During World War II, everyone knew that butter, gasoline, and other commodities were being rationed. But some critics argue that rationing of health care is already going on in the United States. Is it possible for resources to be rationed without public knowledge of it? As a hypothetical exercise, assume that you are a journalist who has just discovered that a local hospital routinely makes decisions about health care based on the age of the patients. Write a short newspaper article bringing public attention to the practice.

4. Hentoff argues that Callahan’s proposal is class biased—that is, it discriminates against the poor—because people with money can purchase any amount of medical care they want. Is this argument convincing? Is there any alternative to this arrangement? Does Hentoff’s point, if valid, destroy Callahan’s argument?

5. At the end of his article, Hentoff argues that the Callahan proposal deprives an entire class of people of the “equal protection of the laws,” and he cites the Dred Scott case (1857), in which the U.S. Supreme Court, in essence, decided in favor of slavery. Is age-based rationing, like slavery, a kind of discrimination? In what ways is age discrimination like or unlike race discrimination? Assume that you are a lawyer arguing this issue of age-based rationing before the U.S. Supreme Court. Write a “brief” based on Hentoff’s general idea and offer your strongest possible arguments to convince the justices.

6. Brody suggests that the ethical debate on health care rationing is now shifting from rationing to the avoidance of waste. Further, he asserts that his little-noticed shift has important policy implications. Discuss what these and other implications might be.

7. Some critics argue that figures show that Callahan’s proposal, if adopted, won’t really save
much money as long as rationing is limited to people over age 75. If their figures are correct, should Callahan be willing to lower his age limit to 70 or 65? Why or why not?

8. Managed care depends on some form of gatekeeping to decide who will get services. What are the ethical dilemmas involved in gatekeeping? What can be learned from considering the activities of gatekeepers in other domains—for example, college admissions officers or caseworkers in the welfare system? Imagine that you are a gatekeeper and you’re faced with a situation in which it might not be possible to provide a questionable service needed by an older person. Write a memorandum to your boss giving arguments on why the service should be provided.

Suggested Readings


Student Study Site

Visit the Student Study Site at http://study.sagepub.com/moody9e for these additional learning tools:

- Flash cards
- Web quizzes
- Chapter outlines
- SAGE journal articles
- Web resources
- Video and audio resources
Controversy 5

SHOULD FAMILIES PROVIDE FOR THEIR OWN?

In a European folktale, there is the story of a farmer who grew tired of his old father sitting at the family table, so he banished him to a hut, where the old man was forced to eat from a wooden trough. One day the farmer discovered his own young son playing with some pieces of wood. “What are you doing?” asked the farmer. The boy replied, “I’m making a wooden trough for you to eat from when you grow old.” After that the elderly father was restored to the family table.

The Beatles famously sang “I get by with a little help from my friends.” But, in truth, when we reach advanced age, most of us get by with help from family. In 2015, more than 43.5 million family caregivers in the United States were providing care to an adult 50 years and older with limitations in activities of daily living (15.7 million family caregivers provided help to an elder with Alzheimer’s disease or some other form of dementia). An even larger number were providing care at some time over the course of a year, with an estimated dollar value of $470 billion in 2013, a big increase from the estimated $375 billion in 2007 (AARP Public Policy Institute, 2015).

The vast bulk of care for frail older adults, perhaps 80%, is furnished by families and other private individuals. So, in response to the question “Should families provide for their own?” the answer is, they already do. But the American family is changing at the same time that American society is witnessing changes in the proportion and character of the aging population (Cherlin, 2010; Qualls & Zarit, 2009). Families are facing new challenges to give care and help, as well as bearing the cost of long-term care for older members (National Institute on Aging, 2011).

With demographic changes under way, the magnitude of the problem is likely to get worse. As aging baby boomers retire, the number of those in the labor force will remain almost constant up to 2030. But during that same period, the number of Americans over age 80—those most in need of care—is projected to increase by almost 80%. As boomers themselves reach their 80s, the caregiver support ratio will continue to decline and even fall dramatically, as shown in Exhibit 21 (Redfoot, Feinberg, & Houser, 2013).
Older Americans have a rich and extended family life. For example, in the United States in 2014, 70% of men and 45% of women ages 65 and older were married, and most of them have adult children (Administration on Aging, 2015). An equivalent proportion have at least one brother or sister, and three quarters are grandparents. According to the Administration on Aging, more than two thirds of older noninstitutionalized people live in a family setting. These facts show that the popular image of old people as lonely and abandoned is inaccurate.

But advanced age frequently brings a need for caregiving. Indeed, caring for older adults has long been a major and predictable part of the life cycle of Americans (Connidis, 2009). Among married couples, the primary caregiver tends to be the healthy spouse. A big problem for old-old couples (ages 75-84 years) is that with advancing age, older spouses are...
increasingly likely to be impaired. In that event, older people typically turn for help to adult children, who are also the chief caregivers for older men or women who are no longer married or whose spouse can no longer care for them (National Alliance for Caregiving and AARP, 2009). Some patterns of caregiving over the life span are illuminated by the exchange theory of aging, which is the idea that interaction in social groups is based on reciprocal balance (Dowd, 1975). The idea of exchange here expresses a concept of “moral capital” or internalized norms of obligation (Silverstein, Conroy, & Gans, 2012). Thus, parents care for children and spouses care for one another because they are motivated by both moral obligation and the knowledge that they can count on reciprocal help in times of difficulty (Raschick & Ingersoll-Dayton, 2004). As seen in Exhibit 22, the majority of people providing long-term care for older adults are unpaid caregivers.

Many different kinds of family members can be involved in caregiving, but responsibilities tend to be divided according to gender. The overwhelming majority of care for aged relatives is still provided by women, typically wives, daughters, or daughters-in-law, who must balance the responsibility of care for the aged with the demands of employment and their own families. The term sandwich generation describes the impact of such caregiving responsibilities on middle-aged women who have heteronormative lives (Brody, 1985, 2004; Neal & Hammer, 2007). Interestingly, in a recent survey of family caregivers, lesbian, gay, bisexual, and transgender (LGBT) respondents were more likely than other respondents to have provided care for an older family member or friend in the previous six months (MetLife, 2013a). As research on aging and later life continues to become more diverse in its focus, we’ll be interested to discover how the experiences of LGBT family caregivers and older adults compare to the experiences of the “typical” family caregivers and care recipients featured in most studies (Movement Advancement Project & Services and Advocacy for GLBT Elders, 2010).

Decades ago, Watkins, Menken, and Bongaarts (1987) estimated that the average American woman will spend more years caring for older parents than she will spend caring for children under age 18. This pattern has continued into the 21st century for many women. However, this generalization overlooks the fact that caregiving may entail different levels of responsibility: For some, it is a weekly telephone call; for others, it is round-the-clock support for someone with Alzheimer’s disease or for someone recovering from a stroke. Still, it remains true that for many women during their midlife years, that time will be spent with caregiving obligations.

In cases of extreme frailty or dependency, the burden on family members may prove exhausting, leading to burnout and perhaps even elder abuse or neglect. The burdens created by Alzheimer’s disease and other varieties of dementia are a case in point. As the disease progresses and the patient’s behavior becomes more extreme, caregiving stress can become almost unbearable in a home setting (Corbin & Strauss, 1988; Springer & Brubaker, 1984). These conditions have led gerontologists to speak of family caregivers as the hidden victims of the disease (Zarit & Talley, 2014). There are important family and social justice questions to be asked about the life course impact for women of being expected to assume elder caregiving responsibilities in addition to other family caregiving and professional responsibilities, not to mention personal development (Wisensale, 2005).

The gloomy portrait of caregiver burden, however, should not be exaggerated. Many caregivers remain in their roles for a long time and never “burn out.” There is a normalcy to family caregiving, especially between spouses, that makes it seem nonextraordinary to those who render care.
Moreover, significant help for caregiver burden exists. Social supports, especially the informal support of family or friends, can prove helpful for caregivers under stress. In addition, caregivers may benefit from **respite care**: temporary care for dependent older people to allow the caregiver some time off (Montgomery, 2012). Such programs can relieve some of the strain involved in efforts to delay placing an impaired or severely ill relative in a nursing home. Mutual-aid groups, such as those sponsored by the Alzheimer’s Association, have also proved effective for caregivers. In all of these cases, formal support services complement informal care, serving not to replace it, but to support it. Last, there are national and state organizations that provide current information and resources to family caregivers, such as the Family Caregiver Alliance.

**Abandonment or Independence?**

There is a persistent stereotype that older people are abandoned by their children, but this stereotype is largely inaccurate. In an important, early study on family support in later life, nearly half of older adults reported that they lived or expected to live in proximity to their children, two thirds within 30 minutes of a child (Shanas, 1980). Currently, more than 40% are in daily contact with their children, and three fourths talk on the phone at least weekly with their children. Older people whose families are spread out geographically do not necessarily consider their families broken up or believe that the young have abandoned the old.

Nonetheless, a clear trend toward independence in living arrangements among older adults has been apparent for a long time. For instance, in 1960, only one fifth lived alone; by 1984, the proportion had increased to one third, and this trend has continued into the first part of the 21st century. Sharing a household in an **extended family** has also dropped significantly in recent years. According to the Pew Research Center, by 2008 nearly 50 million Americans, or 16% of the total population, were living in a household with two
adult generations or a grandparent with another generation. When we look at 1980 figures, it was only 12% of the population, so there has been some significant growth in multigenerational households. During the first part of the 21st century, largely because of economic recession, there has been an increase in multigenerational families (Fleck, 2010), and it seems that this trend may continue (Pew Research Center, 2010). (See Exhibit 23.)

Nonetheless, the sentimental image of the multigenerational family in the “good old days” is mistaken in several ways. In Europe and the United States, multigenerational living arrangements were never common, even in agrarian societies centuries ago (Laslett, 1972). Idealizing the extended family—that is, several generations—living under one roof is part of the “world-we-have-lost” myth (Laslett, 1965/1971), in which we idealize the golden age of preindustrial society. Yet Western societies have tended toward a separate residence for the nuclear family—that is, only parents and children—for a long time. There is also a common stereotype of older people as isolated from others. Yet a majority of older people live with others: around half with their spouses, another 14% with other relatives, and smaller numbers in other living situations. Even those alone are usually within a close distance of relatives or only a phone call away. Fewer than 1 out of 20 are socially isolated, and usually they are so because they have lived that way most of their lives.

Families today typically remain in close and frequent contact, increasingly through the Internet and social media (Hogeboom & Bell-Ellison, 2010). This pattern has been called intimacy at a distance, and it reflects a common desire by older people to live independently yet still remain close enough to have regular contact with grown children. When illness or need arises, a spouse, an adult child, or another relative is typically the first to help.

Exhibit 23  Share of Adults 65+ Living in a Multigenerational Family Household, by Gender, 1900–2008

We do need to recognize that the living arrangements of older people today are different from those of a century ago. One reason for change is simply demographic. Today, unlike in the past, vastly larger numbers of older people survive into advanced age and thus require sustained help with activities of daily living. In cases of debilitating chronic illness, such as stroke and Alzheimer’s disease, older people may live many years in conditions of dependence that exceed the capacity of family caregivers. Other older people may never have been married or may simply outlive available family members. The result is that we must increasingly rely on government to provide what families are not in a position to give.

**Family Responsibility**

The development of social welfare programs for older people, such as Social Security and Medicare, has meant that health care and income support for the aged have become a societal responsibility, rather than a family obligation. But in the United States, unlike other advanced industrialized countries, long-term care has remained largely a family responsibility (Cox, 2015). Government has been reluctant to provide coverage for long-term care, so families remain an important source of both hands-on care and financial support. When it comes to long-term-care needs, older people first rely on spouses or partners; spousal responsibility is deeply embedded in our culture as a matter of both ethics and law. If a spouse or partner is not available to provide care, then other family members such as children and siblings take responsibility. The situation becomes even more complicated for older adults living with same-sex partners and for single and childless older adults. We must ask the questions: Who will care for older adults who don’t have family members available to care for them? What barriers to support and resources will LGBT older adults face when providing care for their partners?

In some cultures, such as the Chinese, Confucian teachings inculcate filial piety or strong reverence for parents, including the duty to support parents over one’s own children (Ikels, 2004). As recently as 2013, a law was passed in China mandating that family members visit their elders (Wong, 2013). In the United States, filial responsibility—that is, responsibility for care of the aged by adult children—is treated ambiguously as a matter of law, custom, and ethics (Callahan, 1985; Pillemer & Luscher, 2004; Post, 1989). In fact, half the states have laws on the books that could compel children to give financial support to aged parents, but these laws have rarely been enforced (Harkness, 2014) partly because of deeply conflicting public attitudes toward filial responsibility. In contrast, Singapore has begun enforcing stringent laws of compulsory filial responsibility that allow older people to sue their adult children for support (Rozaria & Kay, 2014).

In the United States, however, filial responsibility continues to be practiced not as a matter of law, but as a matter of ethics or custom, and although gerontologists have documented rich intergenerational ties in American families (Pfeifer & Sussman, 1991), these ties—and the expectations they bring—are not uncomplicated (Funk, Chappell, & Liu, 2011). One unresolved question is how government programs should interact with spousal and filial caregiving duties and financial responsibilities, and this question is faced by societies around the world (Bengtson & Lowenstein, 2003).
Under Medicare, the U.S. health care system provides near-universal coverage for acute diseases among the old. A majority of Medicare beneficiaries do not realize that, in fact, Medicare does not cover long-term care to any great extent. Financing of acute and long-term care remains separate. About half the money spent on long-term care in nursing homes comes from some branch of government, chiefly Medicaid, and Medicaid is the primary payer for two thirds of nursing home residents (DeNardi et al., 2011; Hagen, 2004).

Medicaid, a joint government program supported by federal and state funds, was created in 1965 to provide health care for the poor. But over the years, it has become the primary...
government mechanism to pay for long-term care for older adults and people with disabilities. Medicare pays only 22% of those long-term-care costs; Medicaid pays 43% (Families USA, n.d.; Kaiser Family Foundation, 2012). Medicaid is a large and expensive program, and its cost is increasing rapidly. As the number of oldest-old (85+ years) in the population increases, long-term-care expenses are likely to become even higher. It is important to note that the number of older people in nursing homes and other long-term-care facilities has been declining in recent decades. AARP researchers estimated that, from 1984 to 2004, the numbers fell by 37%. As a result, the cost to Medicaid for institutional care would have been up to $24 billion higher by 2004 if rates of utilization had remained the same (Redfoot & Fox-Grage, 2013). But will families be able to provide care outside of institutions at the level they have in the past?

GLOBAL PERSPECTIVE

Singapore’s Law Requiring Support of Aged Parents

The Bible’s Fifth Commandment says “Honor thy father and thy mother.” At least one country, Singapore, has passed laws making this duty legally enforceable. Singapore, a small city-state in Southeast Asia, holds adult children legally responsible for support of their aging parents. Other nearby countries, such as Malaysia, subsidize adult day care or other support services to help children care for older parents. In traditional Asian societies, the old would live in extended, multigenerational households and depend largely on their adult children for support and care. But today that traditional family support system is less viable. Singapore is unique in its Maintenance of Parents Act, passed by its legislature in 1995.

In its first years of operation, more than 400 parents petitioned a tribunal to compel their children to support them. The court has some discretion in case children were neglected or abused, and orders for maintenance for parents take into account adult children’s duty to maintain spouses and children of their own. But four out of five elders have obtained court orders compelling their children to support them. Court administrators note that often the adult children who were negligent had become unemployed or were too busy to pay in a timely fashion.

Singapore’s law reflects several assumptions: first, that the family, rather than government or society, should provide care for older people; second, that children have the financial means to support their aged parents; and, third, that older people actually want more direct care from their families. Although Singapore is distinctive in its approach to filial piety, its law is not entirely unique. Countries including India, Israel, and Taiwan have had laws enforcing support for aged parents, and Britain had such a law itself until 1967. A number of states in the United States, including California and Illinois, have similar laws, but they are rarely enforced. Those who supported Singapore’s law argue that it promotes traditional family and religious values and offers government sanction as a last resort.

Although created as a health care program for poor people, Medicaid has, in fact, become a key factor in nursing home coverage for middle-class older people (Redfoot et al., 2013). Three fourths of Medicaid recipients are low-income parents with children, but these families receive only about a quarter of total Medicaid dollars. About two thirds of all that Medicaid spends goes to institutional care for people who have physical or mental disabilities or are older.

Financing Long-Term Care

Presumably, middle-class families rely on Medicaid for long-term care because they do not have the financial capacity to bear the cost of care (Borella, De Nardi, & French, 2016). Long-term care already consumes a larger portion of the private health care dollar for older adults than any other type of expenditure. In 2012, the average cost of a year in a private room in a nursing home was $90,520 (MetLife, 2012a). Few individuals or families can afford that cost on an extended basis. Of those who enter a nursing home as “private-pay” patients, after only three months, nearly 70% have reached the poverty level, and within a year, 90% are impoverished.

In the likely event that long-term-care costs exceed savings, those who face such costs have few options. One option is to qualify for Medicaid. But Medicaid is a means-tested entitlement program. That is, it makes use of eligibility rules based on income and assets to determine whether people qualify for Medicaid coverage. A nonmarried applicant for Medicaid can keep nonexempt assets of only $2,000 or less, excluding the value of a home. Married couples, taking advantage of recent changes in the law, could keep up to $95,000 under the community spouse asset allowance, with all but this limited portion of assets assumed to be available to pay for the partner’s long-term care (O’Brien, 2005).

Many of those who do not qualify for Medicaid still do not have enough assets to pay for long-term care themselves. They face a cruel choice: struggle to provide home-based care or do what is necessary to obtain Medicaid. To qualify for Medicaid, it is necessary to spend down lifetime accumulated assets to become impoverished and thereby eligible for assistance (Wiener et al., 2013). Under regulations of the Medicaid law, spouses of those thus impoverished may obtain some protection, but children and grandchildren lose their share of accumulated life savings. One major problem with Medicaid financing of long-term care is that it introduces inequities across families, age groups, and social classes (Arling et al., 1991). For example, should people who become poor in old age be treated the same as those with a lifetime of poverty? Should families that contribute their own labor for caregiving have that contribution taken into account?

According to public opinion surveys, 82% of the general public recognize that they cannot afford to pay the cost of long-term care either at home or in a nursing home. They also know that they cannot rely on the family alone: 86% want the government to help pay for long-term care instead of leaving it entirely up to the family. Significantly, in an era of strong sentiment against taxes, a majority of adults say they would be willing to pay for a long-term-care program with increased taxes.

But despite such clear public sentiment, a universal public insurance program for long-term care is still not available in the United States. On the contrary, Medicaid has become the public program of last resort to pay nursing home costs. In fact, it is the fastest-growing
component of state budgets, and it is increasingly becoming an old-age program. Nearly 40% of all Medicaid benefits go to the older adult, chiefly for nursing home care (see Exhibit 24).

The growing burden of Medicaid on the government has prompted a search for more affordable alternatives. For years, aging advocates have sold the idea of home care to legislators and to the public with the argument that home care is more humane, in keeping with people’s preferences to stay at home, and also more cost-effective. Unfortunately, the facts are not so clear. National demonstration projects and other studies have shown that home care may be more desirable, but it doesn’t necessarily save money. One reason may be the so-called woodwork effect (Caro, 2013; Eiken & Burwell, 2013): Government policy makers are afraid of people coming “out of the woodwork” to demand services that families would have provided otherwise or that weren’t provided before. Once the government is willing to pay, people may ask “someone else” to pick up the tab (Doty, 2000). Many of the same issues arise when we consider the question of whether government should pay family members to give care that they might be giving anyway (Simon-Rusinowitz, Mahoney, & Benjamin, 1998).

It is often said that older people should go into nursing homes only as a matter of their own choice, not for the convenience of the family. But when family members give the bulk of hands-on care, it is not so simple to say that the legitimate interests of the family are to be disregarded (Dill et al., 1987). The reality is that virtually no one enters a nursing home as a matter of choice. Government financing of nursing home care under Medicaid does introduce a certain financial incentive, but few would be inclined to take advantage of this incentive without some compulsion. People go into nursing homes, by and large, as an act of desperation, when the needs of the older care recipient exceed the abilities of the family to provide care and the family members have reached a point where they have no other alternative.

Exhibit 24  Long-Term-Care Spending, 2011


NOTE: Hospital-based skilled nursing facilities are excluded.
As older people and their families have become more aware of the cost of long-term care, middle-class families have found ways of qualifying for Medicaid. In doing so, families have tried to avoid the harsh requirements of Medicaid spend down—that is, impoverishing themselves by spending all income and assets to qualify for Medicaid coverage. Both attorneys and financial planners urge a variety of strategies to enable middle-income families to qualify for Medicaid coverage of nursing home costs. The heart of these strategies comes down to divestment planning, that is, appearing to be poor by taking advantage of legal loopholes to “avoid the Medicaid trap” (Budish, 1995).

The following are some of the key strategies the specialists recommend:

- Transfer assets at least 30 months ahead of applying for Medicaid
- Transfer assets between husband and wife
- Seek protection through a court order
- Keep assets in a form exempt from Medicaid
- Set up a trust account

It is not known exactly how many middle-class older people presently take advantage of loopholes in the Medicaid law to appear impoverished and thus protect their family wealth. But the numbers are large enough to have sustained a rapidly growing body of elder law attorneys, who have now established their own association, the National Academy of Elder Law Attorneys. As Medicaid divestment planning has become more widespread, the practice has attracted criticism. Some equate the practice with the deception used by some poor people to qualify for welfare payments and with schemes by rich people who dodge taxes through loopholes. In 1997, Congress enacted legislation making it a criminal offense to use professional consultation as a way of spending down to qualify for Medicaid coverage.

Regardless of whether middle-class spend down is technically legal, the critics argue that this form of Medicaid planning is socially irresponsible. This moral criticism is another way of insisting that taxpayers in general should not pay to protect the inheritance wealth of affluent families (Freedman, Lomasky, & May, 1983). When Medicaid spend down becomes a form of estate planning, critics say, it is a means of cheating the government and using public money intended for those in genuine poverty. However, it is not possible to
understand what is at stake in this about family responsibility without seeing the importance of inheritance and the intergenerational transfer of assets (Lee, 2003).

It is easy enough to recognize that family abandonment of older members is a myth and to acknowledge that families are already taking care of their own by giving time and effort. But it is not easy to agree on whether families have an obligation to go further and make use of a portion of their assets to pay for long-term-care costs even if doing so eliminates inheritance.

Similarly, we know that informal supports enable frail elders to remain at home when the only alternative might be entering long-term care. But people disagree about whether families should be paid in cash by the government for giving the kind of hands-on care that they customarily give. Knowledge of the facts is essential for debating the issue. However, because at the heart of the debate is the relationship between family members and thus feelings and values are involved, the debate will not be settled by facts alone.

In the readings that follow, which cover the major contours of the debate over the past couple of decades, strong opinions are expressed about whether families should take care of their own and what role government should have in providing long-term care. The first issue is whether people should take advantage of Medicaid eligibility laws. On one side of the debate are Peter J. Strauss and Nancy M. Lederman, both elder law attorneys who believe that families should realistically plan ahead for nursing home costs and that this planning may involve Medicaid. Planning ahead to qualify for Medicaid, they believe, is not immoral or illegal. Don’t make the mistake of thinking that Medicaid is only for the poor, they tell us.

On the other side of the debate, Jane Bryant Quinn finds transfer of assets to be a troubling practice at the borderline of legality and social morality. Quinn voices a widely shared opinion. It seems wrong for some families to preserve an inheritance while others are forced to impoverish themselves to pay for long-term care. In his article, Stephen Moses focuses directly on this phenomenon of impoverishment due to nursing home expenses. Moses urges us to look carefully at the facts about paying for long-term care.

What about directly paying family members to take care of older people at home? C. Jean Blaser rejects any proposal to have taxpayers support payments to family caregivers. Blaser argues that experience has shown that there are dangers of exploitation, fraud, and abuse in such arrangements. For example, when a family member is paid for providing home care services, who verifies that the services were actually given? The vast majority of care is already provided by family members, so if the government were to pay them to do what they do anyway, it would just drive up the total cost of care without any new services being added. Blaser concludes that, instead of direct payments, it is better for government to support family members in their normal caregiving activities.

In contrast, Suzanne R. Kunkel, Robert A. Applebaum, and Ian M. Nelson argue that recent research suggests that concerns about neglect, safety, and fraud have been exaggerated. New evidence suggests that older people at home are quite satisfied if they are able to pay other family members instead of strangers to give them the care they need. For some, this kind of arrangement seems desirable, and most older people in need of care do prefer to have the right to decide who will provide them with what they need. Giving them the right to pay family members is the best kind of consumer-directed health care and should be supported by government policy.
FOCUS ON PRACTICE

Long-Term-Care Insurance

Many middle-income older people and their families have followed the debate over Medicaid coverage of long-term care with great interest. Those who don’t have enough financial resources to pay for an extended stay in a nursing home or who have a desire to pass along an inheritance have to face the dismaying prospect of bankrupting themselves to qualify for Medicaid. An alternative might be private long-term care. But this option has its problems. In 2002, over 100 companies sold long-term-care insurance policies, but by 2012, fewer than 15 companies remained in the market. Large insurers, including Aetna, Humana, and Prudential, all left the market. The reasons go back to diminished demand by consumers, premiums not matched to cost increases, and low interest rates. Still, in 2015 more than 7 million policies were in force. But that number represents only a small proportion of long-term-care expenditures in the United States; out-of-pocket expenditures remain substantial for those without Medicaid coverage (Johnson, 2015).

Because paying for long-term care is an expensive and widespread problem, one might wonder why more people are not interested in it. One answer is that older people and their families mistakenly believe that Medicare will cover such expenses. Another reason is that many policies are simply not affordable when purchased at an advanced age. Only a tiny proportion of the older population can afford to buy private long-term-care insurance. Furthermore, many consumers, as well as state governments, lack confidence in the products on the market (Brown & Finkelstein, 2007, 2011). And, as noted, fewer insurance companies are in the market to sell policies at all.

As long as government funding for long-term care is explicitly income-based or means-tested, as it is under Medicaid, then middle-class older people will look for other means to provide for themselves. Insurance for long-term care is one alternative (Brown & Finkelstein, 2009). The Affordable Care Act of 2010 did include a provision for Community Living Assistance Services and Supports (CLASS), in support of government-sponsored long-term-care insurance. But the CLASS Act was abandoned when it was decided that the program could not be sustainable on an actuarial basis (Saldin, 2015). Some states have promoted so-called partnership programs, involving private insurance combined with Medicaid coverage (Sun & Webb, 2013). But the market for private long-term-care insurance has still remained small.

In 2013, a federal long-term-care commission was convened to offer ideas about financing long-term care. The panel was divided over the question of public or private insurance. The commission did vote in favor of promoting public-private partnerships that let people buy limited long-term-care coverage and later qualify for Medicaid without spend down. But the commission could not agree on any financing mechanism to move forward in this way (Johnson, 2015). Long-term-care insurance remains an idea that works for some, but it is not yet feasible for middle-class people for whom Medicaid is unavailable.
Medicaid is a public assistance grant program, the twin Great Society benefit signed into law along with Medicare by President Lyndon B. Johnson in 1965. Financed jointly by federal and state moneys, it provides health benefits to 35 million low-income people who are aged, blind, or disabled as well as those who are poor.

Although designed to serve low-income people of all ages, Medicaid has become a lifeline for the older adult, providing essential services that Medicare doesn’t—home health care and long-term nursing home care.

Medicaid is the major payer of long-term care for those who can’t afford the average yearly cost of $40,000 or more (more than double that amount in some areas). Medicaid covers the “nonskilled” but unbelievably expensive custodial care services that Medicare doesn’t. Thousands of middle-income Americans have found themselves divesting themselves of their assets or “spending down” to eligibility levels in order to qualify for benefits under Medicaid. Medicaid pays for 42 percent of all nursing home costs nationwide. It covers over 60 percent of all nursing home patients.

Administered by the states, Medicaid represents the fastest-growing component of many state budgets. States pay approximately 45 percent and the federal government 55 percent of Medicaid costs. The federal share amounts to 6 percent of federal outlays. Nearly one-third of Medicaid spending goes to home health services and long-term nursing home care.

Medicaid rules must be understood in context. One target for budget cuts has been the benefits furnished to middle-income people who have made themselves eligible for Medicaid to avoid the astronomical costs of long-term care. Stricter eligibility rules have made qualifying for benefits harder than ever before, and service and program cuts have affected both home care and nursing home care as well as programs such as adult day care. Additional changes and restrictions are being contemplated by Congress and several states. These events make it more important than ever that you understand the rules and how Medicaid works.

Before learning how to qualify for Medicaid, you should understand what benefits you’re trying to obtain. In general, Medicaid pays for doctors and hospital stays, like Medicare. It also provides coverage for long-term nursing home care not covered by Medicare. Nursing homes operate according to a Medicaid plan which requires doctor certification of the need to enter the facility and periodic review of the need for continued care.

Medicaid also covers home health care services, medical supplies, and equipment. It commonly pays for at-home services supplied under state plans for people who would otherwise be institutionalized, covering part-time skilled nursing, home-health, and homemaker services provided by certified home health agencies.

“Spending Down” for Medicaid

For millions of older Americans, Medicaid is the only means by which long-term custodial care...
can be supported. Each year half a million people “spend down” their assets in order to qualify for long-term care assistance available under Medicaid. Some actually pay for their care until their assets are used up. Others purchase “exempt” items or transfer their assets, all legitimate Medicaid-planning strategies to allow them to keep their independence and autonomy without sacrificing their life savings.

These strategies all follow one basic rule. All your income and assets above specified levels must be spent to pay for care before you will qualify for Medicaid. Various planning strategies using statutory exemptions, spousal protections, and asset transfers are described below.

Plan ahead! This is one area in which advance planning is critical. Depending on your circumstances, it may take time to spend down or otherwise divest yourself of your assets in order to meet eligibility levels—and the law imposes penalty periods after transfers before you can qualify for benefits. Last-minute action may not work.

Although financing long-term care in this manner is entirely legal, Medicaid planning has become a major political issue. So many people have been forced to try to qualify for Medicaid benefits that the various methods for achieving that goal are under continuous attack.

Don’t make the mistake of thinking that Medicaid benefits are limited to the very poor. Medicaid is a complex, confusing, but important government program which has become the life-line for many middle-income families who need help paying for long-term care in order to avoid impoverishment.

Originally intended for the poor, it has become the payer of last resort for persons of modest means. Spousal protections for resources and income clearly indicate Congressional intent that Medicaid continue as a program for middle-income Americans. Yet the use of Medicaid to finance long-term care, particularly nursing home costs, has had a profound impact on state budgets and resulted in attempts to restrict access to the program and limit benefits through calls for block grants.

Despite intended overhaul, with the federal government unlikely to increase Medicare benefits in the foreseeable future, Medicaid is likely to continue as the only government-funded program that deals with long-term care.

There may be any number of reasons not to apply for Medicaid, including personal, family, and psychological reasons; quality-of-care issues; and tax consequences. Nevertheless, it is an option that deserves serious consideration. While access to Medicaid is complicated and may not be available to or right for everyone, it is a possible source of financing for long-term care—even for those who may not now imagine they can take advantage of it.
As the population ages, Medicaid spending on nursing homes could easily lurch out of control. That is, unless it’s limited to the people who really need it.

Medicaid is supposedly for the poor. But increasingly, it’s being exploited by the well-to-do. Instead of buying nursing-home insurance or using their personal savings, they’re getting the government to cover their bills.

Medicaid is a state and federal welfare program, providing various kinds of medical assistance to low-income people. Its charter includes nursing-home coverage.

If you need nursing-home care and are too poor to pay, Medicaid picks up the cost. But if you have personal savings, you’re supposed to cover your own expenses.

When your savings drop below a certain level, Medicaid steps in. From that point on, the taxpayers support you for the rest of your life.

Growing numbers of middle- and upper-middle-class people don’t like these rules.

They’re willing to take care of themselves as long as they maintain their health. If a nursing home looms, however, they decide to quit being responsible. They look for ways of leaving their own money to their children, while forcing the taxpayer to provide their care.

I suspect that some of the well-off people who weasel their way onto Medicaid are vigorous supporters of big income-tax cuts. But where do they think the money for Medicaid comes from? Chocolate bars?

In general, their gambits are legal. The state laws on who’s eligible for Medicaid conceal many weak points that let moneyed people onto the rolls.

To me, exploiting these weaknesses is unethical. The question for families is whether money will always trump morals.

In determining whether you’re eligible for Medicaid, the states look mainly at your assets. If your assets are too high, you can’t go on the welfare program. What’s “too high” varies by state.

Married couples might not qualify if their savings exceed $87,000, plus house, car, personal property, pension income and other items. (That assumes one person in a nursing home and the other at home.)

Singles might not qualify if they have more than $2,000 to $4,000 in savings. They, too, might be able to keep a paid-up home and other assets, even though they’ll be in the nursing home for the rest of their lives.

If you give away money to get yourself under the savings limit, there’s a waiting period before you can collect benefits. Anyway, that’s the way the law is supposed to work.

But there are loopholes. So-called “Medicaid planners” use the loopholes to make you instantly “poor.” You can qualify for taxpayer help without a waiting period.

That turns Medicaid into an “inheritance insurance plan for the middle-class,” says Stephen Moses of the Center for Long-Term Care Financing in Bellevue, Wash. Parents go on welfare so they can leave their money to their kids.

Here are some of the Medicaid-planning ideas promoted at a recent Elder Law Symposium in Vancouver, sponsored by the National Academy of Elder Law Attorneys:

- **Cut your spouse loose.** When one spouse enters a nursing home, assets can be moved into the name of the healthy spouse, says attorney Daniel Fish of Freedman and Fish in New York City. The healthy spouse signs a statement, refusing to support the nursing-home spouse. That spouse then goes on welfare (Medicaid). The state can sue the healthy spouse to recover the money, but Fish says that’s “not frequent.” He thinks there are around 100 such lawsuits a year in New York City.

- **Buy lifetime personal care from your child.** You use your savings to pay for that care in advance, and solidify the deal with a written contract. You’re now out of money and can go on Medicaid immediately, says attorney Scott Solkoff of Solkoff & Zelien in Boynton Beach, Fla.

- **Put your assets into a small business or farm.** Medicaid generally doesn’t require you to use business assets to help pay the nursing-home bill, as long as you or your spouse are active in the business in some way. You could even hire someone to start a business for you, says attorney Lee Holmes of Oklahoma City, although he says he’s never done that.

- **Put your assets into an annuity.** The income would go toward the nursing-home cost. But you could arrange for an heir to get payments if you died early.

Bottom line—Medicaid is in serious trouble. The government isn’t spending enough for quality care. The more people with money exploit the system, by not paying for themselves, the worse the care is going to be for everyone.
INCOME ELIGIBILITY

Even substantial income is rarely an obstacle to Medicaid eligibility for the elderly who require LTC. If they have too little income to pay all their medical expenses, including nursing home care, they’re eligible. Medicaid “income eligibility” is determined in one of two ways. According to the Social Security Administration, 35 states and the District of Columbia have “medically needy” income eligibility systems. Those states deduct each Medicaid applicant’s medical expenses—including private nursing home costs, insurance premiums, medical expenses not covered by Medicare, and so forth—from the applicant’s income. If the applicant has too little income to pay for all of these expenses, he or she is eligible for Medicaid—not just for LTC but for the full array of Medicaid’s optional services, which often stretch far beyond what Medicare covers.

No one has to be poor to qualify for Medicaid. There is no set limit on how much income you can have and still qualify as long as your private medical expenses are high enough or, if you live in an “income cap” state, you have a Miller income diversion trust. All anyone needs to qualify for Medicaid is a cash-flow problem—that is, too little income after all medical expenses are deducted.

ASSET ELIGIBILITY

One might ask, “So what?” Everyone knows that people must spend down their assets before becoming eligible for Medicaid. Here again the truth defies the conventional wisdom. Medicaid beneficiaries can easily retain unlimited assets while qualifying for Medicaid LTC benefits, as long as those assets are held in an exempt form. For example, Medicaid exempts one home and all contiguous property regardless of value. A simple “intent to return” to the home keeps it exempt, whether or not anyone resides in the home or the Medicaid applicant has any objective medical possibility of ever returning.

A transfer of the home with reserved special powers of appointment can provide the best of all possible worlds. It can completely protect the home from the reach of Medicaid after the applicable waiting period while allowing the powerholder to retain control of the property and preserve all desirable tax benefits with no exposure to estate recovery. Another tactic is to spend the assets on property that won’t count for Medicaid purposes: a home, a new car, household goods, funeral expenses, and a burial plot. A client can also reduce his net worth by spending money on travel, which many elderly people enjoy.

According to one press account, elder law attorney Howard Black, of Westbury, New York, suggested this technique to qualify for Medicaid: “if the individual happens to have about $82 million lying around, he or she could even buy a painting by Renoir to hang on the walls of the house,” a strategy he calls “burying money in the treasure chest of the house.”

In spite of these generous special exclusions and exemptions, married couples are frequently advised to consider qualifying for Medicaid by getting a divorce. Divorce is one of the more extreme Medicaid planning strategies. A successful divorce, in which both parties are represented by independent counsel, and containing an agreement in which most or all of the couple’s assets are given to the community spouse, can result in almost immediate Medicaid eligibility for an institutionalized spouse.

The divorce option will likely become increasingly attractive to the current generation of wealthy baby-boomers as they near retirement age. They can hardly be expected to willingly give up the standard of living to which they have grown accustomed just because their spouse has suffered a catastrophic injury or illness that requires full-time medical care in a nursing home. It is unlikely that the current generation will feel it is beneath them to preserve their hard-earned assets by taking advantage of poorly drafted Medicaid legislation.
Bottom line, there is no limit to how much wealth people can stash in exempt assets or jettison by means of a calculated divorce settlement to become eligible for Medicaid LTC subsidies.

**MEDICAID ESTATE PLANNING**

On top of these already generous income and asset limits, professional Medicaid planners—including attorneys, financial planners, accountants, and some insurance agents—use other techniques to protect additional hundreds of thousands of dollars for more affluent clients and their heirs. Such techniques include gifting strategies, annuities, trusts, life-care contracts, and dozens of others delineated in hundreds of books, law journal articles, and the popular media. The proceedings of the annual symposia and institutes of the National Academy of Elder Law Attorneys are a rich repository of the creative and highly profitable methods of Medicaid planning.

There simply is no evidence of widespread catastrophic spend-down of personal assets for LTC . . . Hundreds of articles, legal treatises, and books spanning the past three decades are readily available in any law library. I have personally published over 100 columns describing the practice and techniques of Medicaid planning. 

To obtain even more references, one can simply conduct an Internet search for “Medicaid planning” and find more than two million links to sources, methods, and purveyors of artificial self-impoverishment techniques. Similar techniques allow people with substantial income and assets to avoid Medicaid’s ostensibly mandatory estate recovery rules, although states rarely enforce these rules effectively. . . .

Today, Medicaid eligibility can be bought for a legal fee equal on average to one month in a private nursing home. That’s roughly $5,000 or $6,000—very cheap insurance for LTC, especially when it can be purchased after the insurable event occurs.

**MEDICAID SPEND-DOWN**

If Medicaid eligibility rules are so generous, why do so many Americans spend down into impoverishment before they become eligible for benefits? The answer is, they don’t. Dozens of so-called “Medicaid spend-down” studies were conducted in the late 1980s and early 1990s that showed that spend-down was much less common than previously believed. Before those studies, academics assumed that one-half to three-quarters of all people in nursing homes had been admitted as private-pay patients and spent down until their life savings were consumed. Since the spend-down studies, however, we have known that the actual figure is less than one-quarter of nursing home residents who begin as private-pay patients and later convert to Medicaid. And, because none of those spend-down studies distinguished between people who spent down the conventional-wisdom way (writing big checks to a nursing home every month) and people who spent down the Medicaid planning way (writing one check to an elder law attorney), we have every reason to believe that genuine catastrophic spend down of real personal assets is even less than those studies indicated.

**OUT-OF-POCKET SPENDING**

If there is no reason to spend down assets, then why is such a large proportion of LTC spending composed of out-of-pocket expenditures? Again, the answer is, it isn’t. Because Medicaid patients have to contribute their Social Security income toward their cost of care, the percentage of nursing home costs paid out of pocket is really much less significant than it appears. . . .

Fully 86 percent of all nursing home expenditures come from direct government funding (Medicaid and Medicare) plus indirect government funding (spend-through of Social Security income by people already on Medicaid) plus private health insurance, and much of the remainder comes from personal income other
than Social Security (i.e., not from assets). There simply is no evidence of widespread catastrophic spend-down of personal assets for LTC.

**Bottom Line**

Medicaid is not primarily an LTC safety net for people who have spent down into impoverishment. Rather, it is the principal payor of LTC for nearly everyone regardless of economic status. Medicaid provides fewer than half the dollars expended for nursing home care but covers two-thirds of nursing home residents. And because Medicaid residents have the longest stays, the program touches more than 80 percent of all nursing home patient days. Home care is no different. Only 17 percent of home health care costs were paid out of pocket in 2003. The remainder comes from Medicaid, Medicare, and private health insurance.

The fundamental problem with LTC financing is that government pays for so much of it that the public has been anesthetized to the risk and expense of high-cost extended care. People can ignore the risk, avoid the premiums for private insurance, wait to see if they will need LTC, and transfer the cost to taxpayers. Is it any wonder that so few Americans buy private insurance or use reverse mortgages (see below) to finance LTC? Is it any wonder that most Americans who need LTC end up dependent on Medicaid?

**Building on the Facts**

How can we use these facts to save Medicaid as an LTC safety net, restrain its rising tax burden, and improve the program in the process? One thing is certain: as long as Medicaid exempts unlimited assets, most people will not spend their own money on LTC or buy private insurance. A good first step would be to ask: what is the single biggest asset that Medicaid protects from LTC costs? As discussed above, Medicaid exempts the home and all contiguous property, regardless of value, for both nursing home and home care recipients.

How is that fact significant? According to the National Council on the Aging, 81 percent of America’s 13.2 million households aged 62 and over own their own homes. Seventy-four percent of those senior homeowners own their homes free and clear. Altogether, seniors own nearly $2 trillion worth of home equity. That wealth is illiquid, is largely untapped for LTC costs, is totally exempted from Medicaid eligibility limits, and is usually protected against Medicaid estate recovery.

What would happen if home equity, or at least part of it, were at risk for financing LTC? There are ways to liquefy this wealth and put it to use financing quality LTC for frail and chronically ill seniors, without compelling people to leave or sell their homes. Reverse mortgages, for example, allow people to convert illiquid home equity into usable income or assets. Essentially, the homeowner borrows against his home equity, and the lender makes payments to the homeowner based on the homeowner’s age and the value of the home. The payments continue as long as the borrower occupies the property. After that, the loan becomes due.

Reverse mortgages allow seniors to spend their home equity any way they see fit and still remain in their homes as long as they are physically able to do so.

Placing home equity at risk before granting access to Medicaid LTC benefits would relieve the fiscal pressure on Medicaid.

Yet reverse mortgages are rarely used to finance LTC today, because Medicaid obviates the need to tap home equity for that purpose. Placing at least some home equity at risk before granting access to Medicaid LTC benefits would substantially relieve the fiscal pressure on Medicaid, create a stronger incentive for people to purchase private LTC insurance, and add significantly to the number of market-rate private payers that LTC providers so desperately need.

Home equity is the single largest asset protected from LTC spend-down by Medicaid, but there are many others that could also be tapped...
to relieve the financial burden on Medicaid and enhance private financing sources. As discussed above, those assets include one business, burial spaces for the whole family, household furnishings, a car, and term life insurance. . . .

Is it good public policy to use scarce Medicaid resources to indemnify heirs of recipients against the cost of burying their parents? How much could be saved if Medicaid only exempted $1,000? What if Medicaid placed reasonable limits on all the assets the program currently exempts without limit? Is Medicaid’s proper role to protect inheritances or to provide access to quality LTC for the genuinely needy? . . .

THE SOLUTION

When the problem of Medicaid and LTC financing is properly understood, its solution is obvious. Most people will not pay for something the government is giving away. This is true unless and until the product government gives away is so undesirable that people will spend their own money to obtain a better service. That is already beginning to happen as consumers gravitate toward privately financed home care and assisted living to avoid or postpone Medicaid-financed nursing home care. . . .

If we do nothing, the quality of Medicaid-financed LTC will continue to deteriorate. If we allow the current financing system to collapse entirely, there will be no way left for people to obtain access to quality LTC at any level except to pay privately. When that time comes—certainly within 20 or 30 years and probably sooner—there will be no place for aging boomers to go for the private resources to purchase their LTC except their home equity.

If that is where we will end up by sustaining or expanding the status quo, why not spare the American public that pain by implementing policies that place home equity at risk for LTC now? This would not force people to use their home equity, but it would provide the necessary incentive for Americans to protect against this financial risk as they do against other financial risks: by purchasing private insurance. . . .

NOTES

1. This is true in “medically needy” states. In “income cap” states, a Miller income diversion trust achieves the same purpose.

2. See Social Security Administration, “SI 01715.020 List of State Medicaid Programs for the Aged, Blind and Disabled,” http://policy.ssa.gov/poms.nsf/lnx/0501715020. Some “medically needy” states have become “income cap” states and vice versa since Social Security last updated this list.

3. Medical expenses not covered by Medicare can be substantial. They include eye care, dental care, foot care, and (at least until January 2006) pharmaceuticals.

4. Only $2,000 for an individual ($3,000 for a couple) is exempt from the spend-down requirement in most states.

5. Social Security Administration, Program Operations Manual System (POMS), http://policy.ssa.gov/poms.nsf/lnx/0501130100. A small number of “209b” states can require sale of the home if no exempt relative resides in it and the Medicaid spouse is medically unable to return.


8. Quoted in Mary Schroeder, “Elder Law Expert Outlines Features of Asset Transfer, Power of Attorney,” Financial Services Week 3, no. 20 (July 9, 1990): 19. Although it is unlikely that someone would actually shelter such an enormous dollar amount in “household furnishings,” and more recent SSI rules have clarified that personal belongings
actually held for purposes of investment and appreciation are not exempt, the truth is that Medicaid eligibility workers rarely verify the value and kind of Medicaid applicants’ personal belongings and applicants can easily protect substantial assets in this way.


11. Many of these are available from the Center for Long-Term Care Reform, http://www.centerltc.com/bullets/subject.htm#medicaid_plan.


15. National Council on the Aging, “Use Your Home to Stay at Home(tm) Program Study Shows That Reverse Mortgages Can Help Many with Long-Term Care Expenses,” press release, April 15, 2004, http://206.112.84.147/content.cfm?sectionID=61&detail=576. NCOA has not previously been a strong advocate of private long-term care financing alternatives. The organization’s support and encouragement of reverse mortgages as a new funding source for long-term care displays growing doubt among senior advocates that traditional public funding sources like Medicaid and Medicare will be adequate to finance long-term care in the future.

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**READING 24**

**The Case Against Paying Family Caregivers**

**Ethical and Practical Issues**

_C. Jean Blaser_

Paid family caregiving can be the best of care and, unfortunately, the worst of care. This article will detail how paying family can produce the worst of care, and why taxpayers should not support such payments.

This position is based on experience derived from managing the Community Care Program in Illinois, which provides home- and community-based care to over 35,000 older people a month. Eligibility is based on a need for care, as measured...
by a standardized instrument termed the Determination of Need. The instrument assesses functioning with fifteen activities of daily living and instrumental activities of daily living, and for each activity with which the older person has difficulty, the availability of family and informal supports is addressed. Need for care is determined by a look at those activities with which the applicant has difficulty and lacks necessary assistance. In this way, the program is designed to complement and supplement family support, but not replace it.

In the first years of the program, as a result of a policy decision by another state agency, a significant portion of the caseload was served by family members who were paid as personal care attendants. When the program was transferred to the Illinois Department on Aging, detected abuses led the department to close that subprogram, allowing no more clients to have personal care attendants, and to allow payments only to contracted agencies. Since that time, however, a number of agency providers have elected to hire family members as “preferred” workers, assigning them to care for an elderly family member. As a result, the department has a considerable history to draw upon regarding the problems that can occur when a family member is a paid caregiver.

**Exploitation**

Advocates may argue that a policy of paying the family caregiver supports and strengthens basic family values. On the other hand, it can be argued that such a policy exploits family values by paying the family member less than the going “market” rate for provided services.

Under the banner of “consumer-directed care,” states can reduce the costs of home- and community-based care by providing vouchers or direct payments to clients who, in turn, hire their own workers, termed personal care attendants. By avoiding the administrative costs of recruiting, hiring, training, and supervising workers, the cost per unit of service is substantially reduced. The cost is further reduced by not having to pay mandated fringe benefits such as unemployment and workman’s compensation, although most states may pay Social Security taxes on behalf of the client. And, of course, no health insurance, retirement benefits, sick leave, or vacation are offered. Indeed, the states are careful not to pay for these benefits lest they be open to a charge that these workers are state employees and subject to all the benefits state workers enjoy.

It is a well-established fact that reimbursements to homecare workers are inadequate in most areas of the country. In these times of full or nearly full employment, workers can demand and receive higher wages. Because fewer are willing to accept the low salary and lack of benefits paid to personal care attendants, there is a severe shortage of homecare workers.

However, family workers, who can be considered to be a subset of the larger class of personal care attendants, can be an exception to this general finding. Family members are more likely to be trapped into accepting such employment because they are unable to recruit and hire a nonfamily worker. Faced with the prospect of placing their family member in a nursing home, these family workers will sacrifice higher wages to care for their family member at home.

One such family member detailed this problem in a public hearing on providing a “living wage” for homecare workers. She reported a long and fruitless search for a competent and reliable worker. After many experiences of workers not showing up, not performing the requested tasks, or even stealing from the client, she reluctantly decided to quit her higher paying job with benefits to stay with the client as a paid family worker. She was paid minimum wage and received no benefits for this sacrifice. In addition, she again faced the difficult task of finding a replacement whenever she was ill and unable to work, her car broke down, or she needed respite. She felt trapped by a system that did not value caregiving and did not provide sufficient reimbursement to attract a qualified and quality workforce.
In a society that already exploits the in-home worker, the policy of paying family to provide the care simply continues the exploitation and, in fact, may remove any incentive to change. If family members agree to provide the care at a less-than-adequate wage, and if the policy that allows them to do so can be cloaked in the “feel good” language of consumer choice, the pressure to increase wages and benefits for all in-home workers is reduced. And, with other potential workers able to obtain jobs with higher wages and benefits, the client and family are likely to have very little choice but a family caregiver.

**Potential for Fraud and Abuse**

The above discussion focused on the better side of paid family caregiving, where the family member is more reliable, competent, and caring than a nonfamily worker. On the other side of the picture are instances in which the family member defrauds or abuses the client and program.

While the potential for fraud and abuse exists in any social service program, a program in which family members are paid to provide care creates an environment that is particularly ripe for fraud. The most common type of abuse is financial fraud, where the client and the family member collude to report services that were not delivered, in order to collect payments. In some instances, the benefits of the fraudulent payments are shared. Other times, the older client allows the family member to receive the payment, perhaps through a distorted sense of intergenerational transfer.

A recent example of collusion was detected when a case manager conducted an annual redetermination of eligibility for an elderly woman who had been served by the Community Care Program for five years. The assessment was conducted in the home of the grand-daughter, who had been hired by a contracted service agency to care for her grandmother. The client was lying on the sofa and reported she was in great pain and able to do very little for herself. The case manager, who did not speak the language of the client, used the grand-daughter as an interpreter and, when the assessment was completed, the client was found to have scored 79 points, which on a scale of 0 to 100 is very impaired and represents less than 4 percent of the service population. As a consequence, the case manager authorized fifty hours of service a week, to be provided by the grand-daughter.

An alert homecare supervisor, unable to contact the worker or the client at times when the worker was supposed to be serving the bed-bound client, made an unannounced in-home visit and learned from a building manager that the client did not reside in the apartment but, rather, lived in a senior highrise. The supervisor alerted the case manager, who visited the senior housing site and observed the same client participating vigorously in an activity. Upon inquiry, the case manager was advised that the client had lived in the highrise for five years, and was able to function independently. In fact, the supposedly very confused bed-bound client who did not speak English had taken English classes.

In this example, the client and the grand-daughter colluded to defraud the state of more than $48,000 in service payments. In other cases, however, the department has found the family caregiver defrauding the state without client involvement. Through a match of service records with state death records, the department has found cases in which the client has died but the family member continues to report services, forging the client’s name to the service verification records. In another case, the client moved to another state, but the family caregiver continued to bill the state as if services were still being provided. Unfortunately, these examples are not all that uncommon.

A more troubling problem arises when the older person is coerced through intimidation into signing the service receipt. Most often, the older person is fearful of losing support and is threatened with nursing home placement and so signs for receipt of services. But, in some
instances, the older person has been subjected to physical abuse or neglect or financial exploitation. Neglect is the most common type of abuse. Department staff have seen numerous examples of care provided in early morning or late evenings because the family member is holding down another full-time job, or the grandchild is the supposed worker and is using the funds in order to pay for college.

In other instances, the abuse takes the form of financial exploitation. The family member may be dependent on the pension or Social Security check of the client as well as the payment for services to the client. Case managers have reported instances in which the older person is very impaired and in need of more intensive or skilled care than can be provided by the family member, but is denied this needed care because the family member would then lose control of the client’s financial resources. Staff who had talked with one such client reported that she begged for someone to get her into a nursing home and away from her daughter, who was the paid caregiver.

**Increased Administrative Costs**

With such potential for fraud and abuse, homecare providers report having to take extra measures to assure quality service from “preferred” or family workers. First, the agencies report more difficulty in assuring that the workers are trained before they start service and that they participate in required quarterly in-service training sessions. Second, the agencies have had to increase their monitoring efforts, making more calls to the home or making unannounced visits to the home when the worker is supposed to be on duty. Indeed, it is this sort of monitoring that brings to light many of the cases of fraud, as was seen in the case described earlier.

There are limits, however, to how successful such training and monitoring measures can be. In cases in which the family worker fails to attend the required training session or is not providing the care as directed, the agency will often follow its personnel policies for employee discipline and may terminate the worker. When this happens, the worker will simply go to another homecare agency and secure employment. The client will then request to transfer to the second agency and request services from the family member. This “employer hopping” can continue until the worker finds an agency that is willing to hire family members as workers and that is less than diligent in monitoring the delivery of services.

Advocates of consumer choice will argue that such behavior is an example of the client exercising the right to choose a family member as worker rather than a stranger. A less sanguine interpretation is that the family member is exploiting the client and the service system. Otherwise, why is the family worker not content to make the same salary serving a different client, while an unrelated worker serves the family member?

Thus, agencies not only incur increased administrative costs in monitoring workers but may lose clients as a result of either refusing to assign workers to care for family members or detecting and acting upon fraud. And, the agencies that do not diligently monitor the delivery of services may be subject to loss of contracts or even payments for damages as a result of poor or nonexistent care.

**Increased Program Costs**

In addition to the potential for fraud and abuse of the system and the client, there is the potential program cost of a policy to pay family caregivers. The financial impact of such a policy could be significant. If we are to believe the literature, about 80 percent of the care provided to older people is informal and is provided most often by family members. A systematic program to pay these family and informal caregivers, then, could increase program costs as much as five times, with no increase in actual care provided.
In states where the home- and community-based services are entitlements, which is the case in Illinois, a new entitlement, for families with older family members in the area, would be created if a formal policy of paying family workers were to be instituted. It is not too difficult to imagine not only a significant number of families applying for the benefit once they learn of it but also family intrigues about who gets to “claim” Granny.

On the other hand, the more usual case is that the state caps the amount of funds available for home- and community-based services. In such states, the limited resources could no longer be targeted only to those who had needs beyond those that the family could meet or who had no family nearby to provide assistance.

AN ALTERNATIVE APPROACH

The issue of family responsibility has plagued policy makers for decades. Several years ago, as a response to an advocacy effort to establish payments for family caregivers, the Illinois Department on Aging commissioned an opinion survey of the provider network. The results were interesting, with an almost equal number of respondents agreeing with each of the following statements: “strongly support,” “somewhat support,” “somewhat oppose,” and “strongly oppose” paying families to care for their older members. With such a clear lack of consensus, the department sought the middle ground.

Current department policy does not allow direct payment to family members for care but offers services to complement and support the family members in their efforts. Eligibility for services is based upon both impairment and informal support, so that individuals with moderate impairment but no informal supports are eligible, as are those with strong family support but high impairment. In this way, the program acknowledges the need for support and respite for the family. And, if the family is absent or not able or willing to provide assistance, the state will provide for the needed services. With these policies, the family is supported but the negative consequences of direct payments to the family are avoided.

READING 25

For Love and Money

Paying Family Caregivers

Suzanne R. Kunkel, Robert A. Applebaum, and Ian M. Nelson

The recent emergence of options for compensating family caregivers has raised a host of new issues. Paying family members for providing care has brought to the forefront policy questions about the intrusion of public systems into family life; ethical and ideological issues about obligation and accountability; and pragmatic concerns about health, safety, and quality of services. In addition, compensating family members who provide long-term care has added to

the growing dialogue about economics, family values, and the nature of "care work." Understanding the tensions about paying family members to provide care requires an examination of some fundamental assumptions about care and work. What is the difference between the work people do for love and the work people do for money? What does society expect and require families to do for love, without expectation of money? What are the reasonable limits to those expectations? Proponents of compensating family caregivers argue that it is a way to strengthen, expand, and sustain the natural support system. Critics of paid family care worry that compensation for some of the work will erode family obligation, create a strain on the public system, and put older people at greater risk of abuse and poor care.

While direct payment to caregivers is the model of compensation that brings the debate into sharpest focus, it is only one of several types of compensation. In the broadest sense, financial supports for caregivers can include direct payment for services provided, tax credits, unpaid leave, and cash allowances to cover expenses related to caregiving.

Here we focus only on direct payments to family members for caregiving work. The prevalence of this phenomenon has increased significantly over the past decade, as a direct result of the consumer-direction movement in home and community-based long-term care. In a recent inventory, Doty and Flanagan (2002) identified 139 home and community-based support programs with some consumer-directed option; half of these programs offered the option to older clients. Consumer direction is both a philosophy and a practice that emphasizes the right and ability of consumers to assess their own care needs, decide how best to have those needs met, and evaluate the quality of the services provided. One of the meaningful ways that consumer direction has been put into practice is in care-provision programs in which payers (either government or private plans) allow individuals to hire and manage their own workers.

A significant majority of older people who have services that they themselves direct choose to hire a family member (Doty et al., 1999; Dale et al., 2003). Consumer-directed long-term care, then, provides a focus for a review of the issues and evidence related to paying family caregivers. For purposes of discussion, we have categorized the issues as ideological, ethical, professional, and personal-interpersonal. To provide evidence on each of the issues raised under these categories, we rely heavily on two consumer direction programs in Ohio and on the National Cash and Counseling Demonstration and Evaluation project.

**Ideological Concerns and Empirical Realities**

U.S. culture places great importance on the primacy of the family. However, our public policies related to caregiving reflect a reluctance to legislate supports for family care. For example, the United States was very late among industrialized nations to adopt employment policies in support of family caregiving. The number of programs and the amount of public expenditure in support of family caregiving (for children, older people, or others who need assistance) are very low. For these reasons, paying family caregivers represents a significant shift for U.S. policy: use of public dollars to support what had been considered a private and obligatory activity, and the involvement of government in family life.

Critics of paying for family care have voiced a range of specific concerns about how this practice might undermine social values. If informal caregivers are paid, critics hypothesize, there would be a major shift away from caring as part of normal family responsibility. They suggest that in this and other ways, payment would decrease the quality of the caregiving experience for care recipient and caregiver, with paid services substituting for unpaid care now provided. Because family care is the dominant mode of provision in long-term care, such a
shift would place tremendous burdens on public expenditures. Critics also anticipate that the cost increase could be compounded by a likely increase in the number of homecare recipients choosing this more flexible benefit.

To address these concerns, we rely on evidence from recent evaluation studies of consumer-directed programs, in which a high proportion of consumers have chosen to hire family members.

In both the Cash and Counseling demonstration and the Ohio projects, consumers received the same dollar allocation that they would have under the traditional service system. This allocation is based on health, functional, and cognitive status. Consumers are then able to decide on a payment rate for workers, but the total cost is fixed. In some instances, consumers who directed their own care used a higher rate than that paid to agencies; in other cases, the rate paid in consumer-directed care was lower.

In the Ohio programs and in Cash and Counseling there were differing policies on who could be a paid worker. Some programs did not allow spouses to be paid, while others did. All programs paid worker compensation, unemployment insurance, and Social Security taxes. Training needs were determined by the consumer.

Data from the National Cash and Counseling Demonstration and Evaluation found significant increases in the satisfaction levels of both consumers and caregivers (Foster et al., 2003a; Foster et al., 2003b). Consumers in the demonstration, about 80 percent of whom hired family members, reported large and consistently higher rates of satisfaction compared to a randomized control group (Dale et al., 2003; Foster et al., 2003a). For example, more than 90 percent of the demonstration’s consumers older than 65 were very satisfied with their relationship with their paid caregiver, compared to close to 80 percent for the control group (Foster et al., 2003a). Just over one-quarter of control group members felt neglected by their paid caregiver, compared to 11 percent of demonstration consumers. When comparing consumers who hired family members to those who hired nonfamily workers, findings showed significantly higher satisfaction rates (99 percent versus 91 percent) for those with family workers (Simon-Rusinowitz et al., 1998).

Interviews with caregivers also showed large and significant differences in favor of the option of hiring family members. Demonstration program caregivers’ reports of satisfaction showed them to be significantly more satisfied with overall care arrangements and significantly less worried about whether the care recipients had enough help in their absence (Foster et al., 2003b).

There did not seem to be any negative effects on the overall relationship between the paid family caregiver and the consumer. In response to questions such as whether the caregiver and care receiver get along very well and whether the current relationship is better than at enrollment, there were no differences between the two groups (Foster et al., 2003b). Caregivers participating in the demonstration program were significantly more likely to talk with consumers about personal care needs, and the program consumers were significantly more cooperative. Program caregivers also reported significantly lower emotional strain and significantly higher satisfaction with life. In combination, these data indicate that there is no evidence in the demonstration that family relationships are negatively affected by the payment option.

In a telephone survey of Medicaid personal care clients in New Jersey, researchers (Mahoney et al., 2002) found that about 40 percent were potentially interested in a cash option, but older people were 2.7 times less likely than the younger clients to be interested in this option. In addition, in all of the consumer-directed demonstrations, even consumers who do choose to hire their own workers do not always hire a family member. Taken together, the findings suggest that these programs do not bring consumers “out of the woodwork” to use services they would not otherwise seek.
ETHICAL CONCERNS AND EMPIRICAL REALITIES

Some of the concerns about paid family caregiving are related to the values of beneficence and avoidance of maleficence, the desire to do good and to do no harm. These values translate into a heavy emphasis on protection and minimizing risk for those receiving publicly funded services—which critics call well-intentioned but paternalistic. In the early days of homecare, some suggested that in-home service recipients would be at greater risk of receiving poor quality care. Worker fraud, abuse, and neglect were expected to be a much greater problem in the home when compared to the nursing home setting, because there was only limited agency supervision in that venue. Ironically, this same logic has been expanded to suggest that family and other non-agency-based workers present a higher degree of risk than agency-based workers. Anecdotal reports from providers and homecare program administrators have identified concerns about fraud and poor quality provided in consumer-directed programs (Blaser, 1998). In a survey of state-contracted homecare agency administrators, Linsk and colleagues (1992) found that fraud and abuse were the most frequent concerns about paying family members. The concerns ranged from potential exploitation of the system and of the consumer to failure to provide the services that were paid for.

Findings from studies of the previously mentioned demonstration projects and from an evaluation of the California In-Home Supportive Services Program show no significant differences in safety risks between clients receiving agency-based services and those using consumer-directed services. On many variables, consumers under the self-directed model have better health and safety outcomes. For example, in the Cash and Counseling demonstration program there were no differences in accident rates or falls, but consumers with self-directed care were significantly less likely to have bedsores or to have seen a doctor because of a cut or burn (Foster et al., 2003a). The project also reported large and significant reductions in the proportion of consumers with self-directed care reporting helpers arriving late or failing to arrive at all and in rates of theft. A study of the California program, the largest consumer-directed option in the country, reported no differences on a series of health and safety measures that examined such areas as abuse, harmful behaviors, theft, injury, and neglect (Doty et al., 1999).

Data on quality of service also indicate that consumers hiring family members report better care. For example, among consumers hiring family members, the Cash and Counseling demonstration reported large and significant reductions in the proportion of consumers feeling neglected or being rudely treated by workers. These sizable differences also were evident in satisfaction rates in the delivery of care (Foster et al., 2003a). Findings from the California study found self-directed consumers of care to be more satisfied with the quality of their workers and the services provided (Doty et al., 1999). Preliminary results from the Ohio demonstration suggest that consumers who directed their own care rated the quality of services highly, at a level equivalent to those receiving agency-based services (Kunkel and Nelson, 2003).

A final area of concern involved fraud on the part of the consumer or their family. The three sites participating in the Cash and Counseling demonstration invested considerable resources in monitoring the development of the service plan and in reviewing expenditures. Using a social service professional in a support and monitoring role with consumers and a systematic book-keeping system to assist and review expenditures, the effort found minimal auditing concerns.

These demonstration programs clearly support the notion that consumers can make good decisions about their own care, even when family members are providing that care. Paid family
workers did not abuse the system, exploit the consumer, or fail to provide good services. Consumers hiring primarily family members were healthier, safer, and are more satisfied with services. Program funds appeared to be spent according to plan.

Based on evidence from consumer direction, we can argue that paying family caregivers provides an “acid test” for the notion that beneficence and lack of harm can only be achieved in a formal, public system. The success of the consumer-employed family caregiver arrangement suggests that the values of health and safety might be reframed in ways that engage, and give primary voice to, the consumer of services, moving us from paternalism to participation, with no loss of good care and no increased harm.

PERSONAL/INTERPERSONAL
ISSUES: CARE AS A COMMODITY

The caregiver–care recipient relationship can be emotional, intense, and challenging, whether the individual providing services is a family member or not. “Care work” is an inherently problematic concept in U.S. culture. How can something so clearly emotional in content and motivation as “care” be considered “work”? “Paid caregiving” is similarly incongruous. If care is something we give, from the heart, doesn’t the introduction of payment demean that dimension of the relationship? These questions are magnified when the person being paid for care work is a family member.

These difficult philosophical concerns can be better tackled when put into cultural context and translated into more specific questions. When considering the cultural values that shape the debate, we find that the deep concern over maintaining lines between the work we do for love and the work we do for money, between “care” and “work,” is unique to the United States. Linsk and colleagues (1992) document the “remarkable worldwide expansion of provisions in support of caregivers,” and the prevalence of policies of government compensation for family and other informal care providers that has been widespread for a number of years, whereas, as noted earlier, in the United States we have placed greater value on the separation of government and family as a reflection of the value we place on the primacy of the family. That the introduction of public dollars into the private family domain of caregiving would cause concern in the United States is, therefore, predictable.

We can address that concern more directly in the form of two specific and interrelated issues: how and whether payment changes the relationship between caregiver and care receiver, and the difficulties old and frail consumers may have in taking on the role of employer of their own family members. Does payment change the caregiver–care recipient relationship? Probably so. However, the assumption that these changes must be negative has not been borne out by the demonstration projects. In focus groups and phone interviews, consumers consistently talk about the sense of empowerment that they get from being in charge of their own workers and their own services. They also consistently report that hiring their own worker—very often family members—makes them feel more secure and more in charge of their lives. They were more confident that their workers would show up. They were hiring people they knew, people who knew them and their preferences, people they trusted.

In exchange for receiving services from a trusted worker, these consumers are able to give them something tangible in return: money. The demonstration programs typically arrange for the workers’ paychecks to be sent to the consumers, who, as employers, can hand them to their employees. This practice helps to make roles and responsibilities clear and helps to even
out the balance in relationships between the caregiver and the care receiver. Empowered consumers seem to be successful at managing their workers, giving feedback, and making sure that their services are being provided in the best way possible. Earlier discussion in this paper pointed out that fraud and abuse were not significant problems in consumer-employed provider models. This finding, and the overall sense of empowerment and responsibility voiced by consumers, supports the notion that consumers, even when they are old and frail, can manage their workers successfully, even with the overlay of family dynamics.

**CONCLUSION**

Families have long been the bedrock of long-term care, and all indicators suggest that they will continue to be so in the future. Despite this strong foundation, societal changes in such areas as longevity patterns, workforce participation, and family composition suggest that caregiving will grow in both importance and difficulty. Social policy in support of family care must continue to evolve.

Empirical evidence from well-designed research demonstrates that recipients of paid family care are more satisfied, as are the caregivers. Anecdotal concerns about neglect, safety, and negative effects on family relationships have been dispelled in the studies now available. Although the policy debates about paying family members will continue, this work reinforces earlier studies in concluding that caring for love and money is possible, and, for some, desirable. Compensating family workers, and having consumers hire and manage their own workers, can be good for consumers, family members, and the long-term-care system overall.

**REFERENCES**


FOCUS ON THE FUTURE

Genetic Screening for Alzheimer’s Disease?

The year is 2022, and the time is 7 a.m. A voice on your home computer wakes you up. A blinking light on the screen indicates you have overnight e-mail: two messages. One is from your great aunt Mabel. She’s gotten back her genetic screening testing results for Alzheimer’s disease, and the news is not good. They’ve told her the odds of her getting Alzheimer’s are 90%, and she’s pretty depressed by the news. She’s decided that she doesn’t want to live with that prospect ahead of her. Now she’s having trouble finding a doctor who’ll do assisted suicide for her. There are plenty of doctors who do it, of course, but she needs one who’ll accept Medicare assignment for the procedure. Now she wants advice from you.

The other message is from your HMO: It’s time to come in and have a blood test to determine your genetic susceptibility to hypertension and colorectal cancer. Your HMO now requires these new tests for everyone in their plan. They assure you that the genetic test is not for purposes of discrimination: You’re already enrolled in their plan, so you’ll be covered. But by getting genetic information about you, they insist, they’ll be able to tell you how to engage in preventive health practices to limit your risk of a heart attack or cancer. The e-mail message promises that the HMO has your best interests at heart. But if you don’t comply, they warn, you’ll be subject to penalties. Seems like they know everything about you. It’s a good thing they have your best interests at heart, you tell yourself. Time to get on the phone to Aunt Mabel.

Questions to Ponder

Researchers have recently identified a link between Alzheimer’s disease and a specific genetic pattern known as apolipoprotein (ApoE-4). This form of the gene, ApoE-4, appears in around half of those with Alzheimer’s. The other half of those with Alzheimer’s do not carry ApoE-4, so another factor besides the gene must also be at work. Nonetheless, 90% of people who have double copies of the ApoE-4 gene will develop Alzheimer’s disease by the time they reach age 80. People with double copies of ApoE-4 are only 1% of the total population, but their chances of developing Alzheimer’s are about 10 times what they are for people with a different distribution of ApoE genes.

The presence of the ApoE gene in any of its forms doesn’t give absolute prediction of Alzheimer’s. An official statement on genetic testing was issued by a working group of the American College of Medical Genetics warning that DNA tests for Alzheimer’s should not be used for routine clinical diagnosis or predictive testing (Wagner, 1996).

At present, then, the ApoE blood test doesn’t give a definitive prediction of Alzheimer’s, but it is possible, even likely, that a better genetic screening test will be developed in the future. The development of such a genetic test for Alzheimer’s disease raises troubling questions, however:

- There is presently no cure for Alzheimer’s. Are we justified in testing for diseases before any treatment is available?
- Who should be tested, and who will pay for testing? Who will have access to the results?
- How will insurance and health care systems be affected? Will legislative antidiscrimination safeguards be necessary?
The discovery of a new genetic screening test for Alzheimer’s disease raises questions about an individual’s right to know, and the right not to know, about a diagnosis. If there were a reliable test for predicting Alzheimer’s, why shouldn’t people have a right to know the results? But what if that genetic test weren’t as reliable as people believe? Consumers may not understand that the current test yields only a probability estimate. People may mistakenly believe that the test is like a pregnancy test or like screening for Huntington’s disease—tests that yield definitive knowledge. There has already been controversy about using genetic tests for Alzheimer’s disease.

The case of Alzheimer’s testing seems different from, say, cholesterol or hypertension screening, for which knowledge about genetic markers or other predictors can motivate patients to change behavior and reduce the likelihood of illness. In the case of genetic markers for colon cancer, genetic screening can lead to actions that might actually reduce the risk of disease, which is different from Alzheimer’s disease, for which preventive measures are limited. In the scenario presented previously, Aunt Mabel believes that the genetic test has value for her. She has lived a full life and now prefers to end her life, rather than face some likelihood of developing dementia. We might recall that the first patient who died at the hands of Dr. Jack Kevorkian was Janet Adkins, a woman age only 54 who feared that she had Alzheimer’s disease because of ambiguous symptoms.

The availability of a genetic predictor for Alzheimer’s raises important questions for private long-term-care insurance. In the prior scenario, the HMO wants people to have genetic tests for hypertension and colorectal cancer. Private insurers someday might want applicants to undergo Alzheimer’s genetic testing. We could pass laws prohibiting discrimination based on genetic tests. But is it fair to prohibit insurers from using genetic-risk data on Alzheimer’s while the test results remain available to individuals? In that case, it seems likely that individuals who find they have a higher-than-average probability of developing Alzheimer’s are likely to purchase long-term-care insurance, which could overload insurers with big claims—a classic instance of a pattern called adverse selection.

Furthermore, once a genetic screening test for Alzheimer’s becomes widely used, would there be pressure to use it with older people under consideration for prominent positions? For example, John McCain was 72 when he ran for president of the United States in 2008. Should he have been urged to have an Alzheimer’s screening test? In asking that question, we cannot forget that Ronald Reagan was diagnosed with Alzheimer’s soon after leaving office and may already have had it during his second term.

We are only at the beginning of debate over the implications of genetic testing for society, and Alzheimer’s is one of many diseases that will be at the center of this debate. The Human Genome Project has given us detailed knowledge of the entire genetic code, but genetics is not the whole story about human health and well-being. As we have seen, a genetic screening test for Alzheimer’s yields a prediction of probability alone—a message of chance, not of fate. We misunderstand the test if we see too much of our destiny in it. It has been said that it is a blessing that prevents us from seeing our future, especially our future suffering, because each of us can bear more suffering than we can presently imagine. But new knowledge of genetics is likely to enlarge our ability to see into the future in ways we’ve barely begun to consider.
Questions for Writing, Reflection, and Debate

1. Elder law attorneys often argue that transfer of assets is perfectly right because it is permitted by law. Is this argument a convincing one? Imagine that you are an elder law attorney who has been suddenly questioned about your practice by a reporter from a local newspaper. Write a detailed statement defending your practice to be distributed to the newspaper.

2. Elder law attorneys sometimes defend transfer of assets by arguing that Medicare treats physical illnesses differently from Alzheimer’s disease or similar impairments. Is this argument a persuasive one? If Medicare were amended to provide full coverage for Alzheimer’s and related disorders, would transfer of assets no longer be justified?

3. Critics like Jane Bryant Quinn have charged that for older people to deliberately transfer assets to qualify for Medicaid is a form of “middle-class welfare.” Is this charge a fair one? List each of the arguments in favor of and against this charge. Then look over what you’ve written and produce a rebuttal for each argument.

4. Some people who favor the idea of transfer of assets from aged parents to adult children to qualify for Medicaid argue that older people have a “right to leave an inheritance.” Is this a “right” that should be encouraged or discouraged by either Medicaid or the tax system? Who would benefit and who would be harmed if we were to expand that right? Who would benefit and who would be harmed if we were to limit it?

5. Many believe that frail older people should be able to select anyone, including a family member, to provide the services to which they are entitled and have the government pay for that care. Are there any valid reasons for prohibiting the hiring of family members to perform home care services? Draft a letter to your congressional representative suggesting why you think this practice should be permitted or why you believe such a practice is mistaken.

6. Assume you are an assistant to a U.S. senator responsible for drafting an expanded version of a national health care law to cover the whole range of long-term care, from community care to the nursing home. Write a “bill” describing the kinds of services that might be provided to the public under the new law, including the types of conditions covered. Then write an accompanying memorandum for the senator suggesting ways the new services could be paid for. What combination of taxes and fees would cover the full package of long-term-care services?

7. Rhonda Montgomery has written about what most families immediately recognize—namely, that women end up handling most caregiving for frail older adults. Is this fact about gender differences something that the government should be concerned about, or is it an issue best left for families to work out for themselves? If we wanted to correct this apparent unfairness in the burden of caregiving, how could the government make things fairer? What are the risks of setting up a new government program to correct the problem of fairness?

8. Assume that you have a close family member who may need long-term care. Visit the following websites and identify the factors that seem most attractive about the services described on those sites: LeadingAge (Formerly American Association of Homes and Services for the Aging; www.leadingage.org) and Assisted Living Federation of America (www.alfa.org). What questions aren’t well addressed by the information you found at those websites?

Suggested Readings


**Student Study Site**

Visit the Student Study Site at [http://study.sagepub.com/moody9e](http://study.sagepub.com/moody9e) for these additional learning tools:

- Flash cards
- Web quizzes
- Chapter outlines
- SAGE journal articles
- Web resources
- Video and audio resources
Should Older People Be Protected From Bad Choices?

Uncle Bert’s “bad judgment.” The trouble started when Bert, 79 years old and a widower for 5 years, arranged for a housekeeper to come in a few days each week to take care of the house. Lilly at first seemed dedicated to her job, and gradually Bert began paying her extra money to do other jobs for him—like reading to him when his eyes began to fail. Soon it seemed natural for her to help him with his checkbook. Before long, Lilly was staying overnight at the house, and it seemed like Bert was becoming her only job. But Bert brightened up whenever Lilly was in the house.

Several times, when Bert’s nephews or niece dropped by early in the morning, they found Lilly in bed with Uncle Bert. Something was going on with the two of them, but no one knew exactly what it was. One of the nephews told another he was afraid that Uncle Bert was becoming “a dirty old man.”

Another factor in their concern was Lilly’s brother, Shawn, who got involved in the household. Shawn ran a multilevel marketing program selling vitamins and health products door to door. Uncle Bert began taking megadoses of vitamins in the belief that they could reverse his diabetes. He also invested his substantial life savings in Shawn’s business, which was soon being operated out of Uncle Bert’s garage.

When Lilly wasn’t around, Uncle Bert didn’t stay at home. He had a lifelong habit of taking long walks through the city, and sometimes he still walked after dark through dangerous neighborhoods. He frequently walked all the way across town to the dog track, where he would lose a lot of money gambling. Uncle Bert’s nephews and niece were worried about all this and told him so.

But Uncle Bert dismissed their concerns. He said he had a right to spend his money the way he wanted and asked simply to be left alone. “I’m old enough to live as I please,” he told everyone, “and the quality of my life has never been better.”

Some questions about the case of Uncle Bert. Bert’s nephews and niece didn’t like the way he was living. They thought he was acting in ways that were misguided, even dangerous. Specifically, Uncle Bert was acting in ways that put his health and maybe his life at risk. But what do risk and danger actually mean in this case? True, Bert was following unorthodox medical treatments and walking after dark in dangerous neighborhoods. But don’t younger people act in risky ways, too? Does making bad choices or running a risk constitute some kind of self-neglect? Are we ever justified in interfering when a competent adult acts that way?
Does age make any difference in a case like this? The ill-defined relationship with Lilly makes one nephew ridicule his uncle as “a dirty old man.” What can he and his siblings do about any of this? When all is said and done, does Uncle Bert have a right to be left alone? Does he have a right to pursue a romantic relationship even if others think it is ill advised? Bert stoutly defends his own definition of quality of life.

If these questions are troublesome, the problems only became worse as this case progressed: Shawn’s vitamin and health product business was apparently going well, but Bert’s nephews and niece could not see any evidence that the vitamins were helping their uncle. On the contrary, one of them happened to see on the table a copy of Uncle Bert’s income tax return—filled out by Lilly—and it indicated that all his savings had been depleted. The nephews and niece were dismayed in part because, ever since they were little, their father told them that his brother Bert, who was childless, planned to leave his fortune to his favorite nephews and niece, who were his only family.

Still worse, Bert had some small strokes and began using a walker to get around the house. He couldn’t go out much anymore, but still kept taking his vitamins, although not his blood pressure medication. Lilly started staying at the house all the time. Whenever members of the family visited, they tried to ask how things were going, but Uncle Bert seemed confused and also fearful about answering questions. He would act uneasy whenever Lilly or Shawn was in the room. The nephews and niece noticed that his back and neck were bruised. When asked about the bruises, Lilly said Bert had fallen but hadn’t seriously injured himself. It was nothing to worry about, she added.

Uncle Bert’s nephews and niece decided to have Bert’s doctor look at his bruises. In the course of the examination, Bert said things that made the doctor believe Shawn and Lilly might have abused him, so the doctor reported the case to the local adult protective services agency. Within a few days, a social worker came to the door and asked to interview Bert. But Uncle Bert, standing in the doorway with Shawn by his side, quietly told the social worker to go away—he didn’t want any interference in his life.

The Vulnerabilities of Older People

The case of Uncle Bert presents a dilemma. He asserts his right as an adult to make his own choices, but the signs that he is being manipulated or abused are growing stronger and stronger. Bert might be subjected to financial exploitation by people he trusted, perhaps foolishly, in an investment scheme. His money is rapidly being depleted, and there are bruises that may indicate physical abuse. Family members are concerned about his welfare, but they also have an interest in protecting their inheritance. They seem to have reasons for suspecting “undue influence” on Uncle Bert’s decisions (Horning et al., 2013).

How has Bert’s quality of life changed as events have unfolded? From Bert’s point of view, his quality of life seems to be strengthened by being able to do things he has always enjoyed, whether wandering through city neighborhoods or gambling at the dog track. His relationship with Lilly, from Bert’s point of view, was also a favorable factor at first. But now his quality of life has been diminished because he is limited to staying at home. The relationship with Lilly and her brother seems to have introduced an element of fear into Bert’s own home.
Other questions also need to be answered. Was the doctor right to have reported Bert’s case to the local agency that responds to suspected elder abuse? Was Bert acting freely when he rejected outside interference in his life? What should we make of the fact that the family members are concerned about preserving the money for their inheritance? What can be done in a complex case like this?

Such decisions are never easy. Aging does tend to make people more vulnerable physically, socially, and sometimes emotionally. At the same time, however, we know that individuals have different competencies even as they age. We are finding that some of our stereotypes about the vulnerabilities of older people are simply not accurate. Why should the old be protected from risky choices that may be important for their quality of life?

**INTERFERING WHEN PEOPLE MAKE BAD CHOICES**

The dilemmas in this case boil down to a single question: When is it right to interfere with the actions of other people if those actions constitute a danger to them? The law tells us that we are not permitted to curtail a person’s liberty just because that person lacks the ability to carry out decisions without outside help. Thus, a quadriplegic, for example, would not be legally incompetent—just a person unable to carry out decisions made. But it could be proper to intervene if the individual is unable to make decisions at all, say, because of an incapacity to understand what’s going on. That may happen, for instance, in a delusional state or in dementia, where a person cannot understand or evaluate information.

As the case of Uncle Bert began, Bert seemed able to understand the risks he was taking by walking in dangerous neighborhoods or by taking vitamins to manage his diabetes. He simply evaluated matters differently than his family. There was no evidence at all that Uncle Bert was mentally incompetent. Sometimes competent people make bad choices, as we all do from time to time, or choices that others disagree with (but aren’t necessarily “bad”). As the case unfolded, Bert continued to engage in risky behavior—for example, not taking his blood pressure medication. But there was evidence of other threats: first, the suggestion that his life savings was being depleted, and second, signs that Bert might be subjected to physical abuse. Even more disturbing, he seemed “fearful” in the presence of Lilly and Shawn. But in the eyes of the law, Uncle Bert still remained a free and competent adult. If a person wants to put money at risk or remain in a dangerous living situation, he or she is free to do so and is also free to reject help offered from outside.

One reason for intervening might be that Uncle Bert seemed “confused.” If indeed he is unable to make decisions or to understand the implications of his decisions, that might be a sign of diminished mental capacity and could be grounds for intervening, regardless of whether Bert agrees. Note here that there is a difference between a case of potential elder abuse or self-neglect and a case of potential child abuse. An adult, unlike a child, is always presumed mentally competent until proven otherwise. Uncle Bert may be fearful, and he may be in what seems like an intolerable condition of exploitation, but unless we have grounds for doubting his mental competence, we cannot override his liberty.

The case of Uncle Bert’s bad judgment raises many questions and suggests the need for an examination of some basic concepts to understand the issues presented by this case (Pillemer et al, 2015):
• Elder Abuse and Neglect. Older people, like other adults, have a basic right to live in ways that others judge risky or ill advised. At what point does such behavior become categorized as self-neglect and justify intervention? What happens when others are involved who may be the cause of physical, psychological, or financial abuse? When harm is threatened, how do we assess a person’s mental capacity for decision making? Is there a difference between neglecting one’s self and being neglected or abused by another?

• Quality of Life. What is it that constitutes quality of life—in short, what makes life worth living? Could an older person make a judgment that quality of life is more important than quantity—even if it means running risks to health and safety or having relationships that others might regard as unorthodox?

• Sexuality. What patterns of sexual behavior are most prevalent in old age? What is the relationship between sexuality and mental health in later life? What are the signs that an older person is being exploited sexually?

• Crime and Safety of Older People. Are older people more likely than others to be crime victims? Do older people fear crime more than other age groups? What is the impact of crime and the fear of crime on the quality of life of older Americans?

ELDER ABUSE AND NEGLECT

Just how common is elder abuse? Research on elder abuse suggests that this phenomenon is complex (Quinn & Tomita, 1987; Roberto, 2016; Wolf & Pillemer, 1989). There are difficulties in measuring just how much elder abuse occurs because of the way statistics are collected (Heller, 2000) but even more fundamentally because of a lack of consistency in how elder abuse and neglect are defined and explained (Biggs & Goergen, 2010). Moreover, we must look carefully at victims and perpetrators and at the different types of abuse. There is a series of known risk factors for elder abuse, including the presence of psychopathology, especially alcohol and substance abuse; family history of violence; a family member dependent on others for financial support; caregiving burdens; social isolation; and the recent occurrence of stressful life events (Dong, 2015). Lifelong patterns of domestic violence are often reversed when the parent or the formerly dominating spouse becomes less powerful and is now the victim instead of the abuser (Anetzberger, 1987). More recent research has examined the differences and similarities between elder self-neglect and abuse (Dong, Simon, & Evans, 2011, 2013), as well as how these phenomena are considered to be social problems requiring serious public and professional attention (Harbison et al., 2012). As well, there are cultural variations and contexts that have only recently been explored in research on elder mistreatment that are important to take into account (Çevirme et al., 2012; Naughton et al., 2012). In fact, this is a cross-cultural, global aging issue (Penhale, 2010). Lastly, it is important to make a distinction between elder abuse and self-neglect, as they may not be the same phenomenon, despite both pointing to the vulnerability of some older adults.

A recent comprehensive review article by Lachs and Pillemer (2015) indicated that approximately 10% of the older adult population has experienced elder abuse, including physical abuse, psychological or verbal abuse, sexual abuse, financial exploitation, and neglect. But figures are hard to be certain about: Elder abuse can remain invisible and unreported because of fear of retaliation. A federal law, the Elder Justice Act, was
passed in 2010 to provide resources for prevention and detection of elder abuse, but funding levels remain uncertain (Daly, 2015). However, there has been a recent intensification of efforts on the part of the Centers for Disease Control and Prevention to develop a set of uniform definitions of and recommendations for addressing elder abuse (Hall, Karch, & Crosby, 2016). Elder abuse is now being recognized as a significant problem in our society (Summers & Hoffman, 2006).

Physicians and home care workers are often in a position to identify preliminary signs of potential elder abuse, and lawmakers have addressed the problem of reporting elder abuse. All states now have formal reporting arrangements for suspected cases of elder abuse. Today, laws in 42 states require mandatory reporting whenever there is evidence of abuse (Daly et al., 2003).

But some advocates have questioned the effectiveness of mandatory reporting. Reports do not necessarily lead to any follow-up action because in-home services may not be readily available (Silva, 1992). Furthermore, as in Bert’s case, not all instances of abuse are readily apparent. When we broaden the issue to include self-neglect, it becomes even more difficult to draw clear lines, especially when an older person simply insists on living his or her own life, independent of interference by outsiders.

When professionals come across cases of suspected abuse or neglect, they face significant challenges and complex questions (Gergeron & Gray, 2003). If they report the matter to authorities, are they violating privacy or confidentiality? How serious do the signs have to be to prompt reporting people against their will? What happens if accusations turn out to be false? Could reporting a case of potential abuse make matters worse? These questions bring us to the heart of the controversy about whether older people should be protected from bad choices.

### URBAN LEGENDS OF AGING

“We need more regulation of nursing homes to prevent elder abuse.”

Actually, on paper, the nursing home industry is already more highly regulated than any industry in the United States, except for nuclear power. As for elder abuse, it’s more likely to happen—and remain undetected—in a home care setting. Citizens’ groups could certainly contribute by closer consumer scrutiny and advocacy of nursing homes. But more regulations may not help since we’re not enforcing the ones we already have.

### PERCEPTIONS OF QUALITY OF LIFE

In the case study of Uncle Bert’s family, his doctor and a social worker questioned whether Bert was taking unreasonable risks—making bad investments, exposing himself to the danger of crime and abuse—to live independently. Bert believed that he alone had the right to define the quality of his life. At age 79, he may have felt he had lived long enough to make his own decisions about risks and benefits. With regard to money, there
is an important relationship between subjective well-being and financial control of one’s life. Quality of life in old age may be tied to an individual continuing to exercise control over money (Cutler, Gregg, & Lawton, 1992), but exercising control and making choices mean running certain risks.

Debates about risky behavior and mental health in later life often come back to an ambiguous phrase: *quality of life* (Schulz & Morycz, 2013). Defining quality of life and measuring well-being in old age are serious problems for gerontology and present many challenges for measurement and theoretical interpretation (Kane & Kane, 2000). Broadly speaking, life satisfaction can be defined as a person’s attitude toward past and present life as a whole. In contrast, morale is a specific feeling, whether optimistic or pessimistic, about the future. These psychological concepts, along with happiness and mood, are obviously important. But notice that they address the issue of subjective well-being in later life, which is ultimately an individual’s own perception.

To measure subjective well-being, gerontologists make extensive use of an instrument called the Life Satisfaction Index, which considers items such as zest and apathy, self-blame, attainment of life goals, and mood (Meléndez et al., 2009). The Philadelphia Geriatric Center Morale Scale has also been used to measure subjective well-being. Chronological age by itself is only weakly correlated with subjective well-being; in other words, old age in and of itself is not necessarily a cause of poor morale or unhappiness. Physical health, however, especially self-rated health, is a strong predictor of subjective well-being. Health problems, of course, are more common in later life, but subjective rating of one’s own health reflects individual coping style and not simply objective physiological function. In fact, self-report measures often are more positive than objective health status measures for the same individual. We cannot ignore individual capacity for adaptation.

Relationships are another factor in subjective well-being. Is Uncle Bert’s living situation—cuddling in bed with his housekeeper—a pattern of adaptation that we could call successful aging? The mere existence of relationships does not prove that people are aging well; more important is the quality of those relationships (Adams & Blieszner, 1995). We can’t simply analyze the numbers of social networks or kinship patterns to measure well-being. Older adults need to develop relationships with people who help them in ways they want to be helped, whether those people are family, friends, or others. No single pattern of personal relationships is optimal for all people as they age, and human beings require intimacy and love throughout the life course, including later life.

**Sexuality in Later Life**

Uncle Bert’s nephews and niece were uneasy about the possibility of their uncle having a sexual relationship with Lilly. To them, it seemed inappropriate for a 79-year-old man to have sex with a much younger woman without being married. In all likelihood, Uncle Bert’s nephews and niece had some misconceptions and stereotypes about late-life sexuality (Butler & Lewis, 2002). Sex among older adults has long been a topic for humor, even in Roman comedy and the poetry of Chaucer. But of 106 traditional societies studied around the world, in only 3 did sexual behavior among the aged violate social mores. In Western culture, however, though sexuality is part of being human and sexual intimacy is a normal
aspect of later life, it is still often considered unusual or a subject for humor or judgment by younger people (Kaye, 1993).

The normal aging process is less a determining factor of adult sexuality than are marital status, general physical health, or the feelings of an older person about sexuality are (Hillman, 2000). Complete cessation of sexual activity is most often a result of a decline in the physical health of one or both partners. But sexuality is much broader than sexual intercourse. We need to remember that older people, like younger adults, need intimacy of all sorts to be happy and healthy, and that individual variability exists in terms of what people need, want, and enjoy.

In fact, studies by sex researchers Masters and Johnson (2010) have shown that female sexuality has no time limit and that male sexual capacity may extend into the 80s. However, sexual activity in late life is most clearly accounted for by the continuity theory of aging. The best predictor of sexual behavior in later life is earlier sexual behavior. The biggest limiting factor, especially for women, is the availability of a partner.

A key feature of late-life sexuality is its multidimensional character; sensuality, intimacy, and touching are all at least as important as intercourse. Nevertheless, one Swedish population health study found that, among 70-year-olds, 46% of the men and 16% of the women still found enjoyment in sexual intercourse.

The contrast between the figures for men and women mostly reflects the changing sex ratio in later life. Exhibit 25 shows the discrepancy in the numbers of older men and women now, and projected into the future. In 2015, older men were outnumbered by older women—20.4 million older men to 25.9 million older women. The reason for the imbalance is that women tend to outlive men by an average of 6 years, and they tend to marry men who are about 2 years older. With advancing age, therefore, widowhood takes its toll: In 2015, 34% of all older women were widows, compared to 12% of all older men, nearly three times as many widows as widowers. And older men are more likely to be married than are older women (Administration on Aging, 2015).

Assuming that the opportunity exists, most older men and women can enjoy sexuality in later life. Men can maintain fertility and generate sperm into their 80s, although men in their 70s are more likely to be worried about sexual function and sexual performance than men in middle age (Panser et al., 1995). Like women, men experience hormonal changes as they age, but men do not experience a distinct climacteric phase during which they completely lose reproductive capacity. Older men do experience a slowing down of the speed of sexual responsiveness, and they and their partners need to adapt to these changes. As continuity theory suggests, men’s pattern of earlier sexuality is the best predictor of their sexuality in old age.

A major difference between the sexes is that, by the end of middle age, women experience menopause and loss of fertility. The decline in hormones that causes menopause is usually gradual, and thus menopause need not be a traumatic event. With longer life expectancy, menopause can actually be an opportunity for a second adulthood. Menopause does bring distinct physical changes, however. For example, decreased production of the hormone estrogen can increase the risk of osteoporosis (Shapiro, 2003). Traditional images of women’s late-life sexuality have sometimes been quite negative (Covey, 1989), but literature abounds with examples of vigorous post-menopausal female figures, such as Penelope in Homer’s Odyssey, Chaucer’s Wife of Bath, and several heroines in Shakespeare. Modern writers such as Toni Morrison and Alice Walker have picked up on these positive themes of late-life development (Banner, 1993), and Gabriel García Márquez’s Love in the Time of Cholera offers a vivid portrayal of passion in later life embodied in the character of Fermina Daza.
In the case study that opened this chapter, Bert seemed unaware that he might be taken advantage of, whereas his nephews and niece thought his attitude proved his incompetence. Who is most qualified to determine whether an older person is likely to be exploited or be the victim of a crime? Actually, well-established statistics show that Uncle Bert’s experience and judgment might better match reality here. Perhaps his nephews and niece are fearful because the media give heightened attention to crime against the old. But the facts suggest a different picture. Annual figures from the National Crime Victimization Survey show that, compared to other age groups, people ages 65 and older experience lower rates for serious crimes such as robbery, personal theft, assault, and rape (Bachman, 2014). When all crimes are taken together, the victimization rate for older adults is lower than the rate for the rest of the population (Klaus, 2000). Is Uncle Bert safe when he walks in the dangerous parts of the city at night? Not necessarily. Crime against persons of any age may be more likely in certain local areas. If an older person does become a crime victim, then the aftereffects—for example, from serious injury—can be more long lasting than for a younger person.

Whatever the actual incidence of crime, fear of crime is widely believed to be more common among older people than among younger people (Oh & Kim, 2009). The popular stereotype of older people becoming “prisoners in their own homes” because of fear of crime is exaggerated.

The biggest threats to older people may come from financial exploitation (Jordan, 2002), considered to be the crime of the 21st century, according to the National Council on Aging (n.d.). Older adults are vulnerable to frauds and scams, as well as pickpockets, purse snatching,
and checks being stolen from the mail. Then, too, there are borderline abuses by con artists and unscrupulous advisers. A study of randomly selected older people in Canada found a much smaller proportion—only one half of 1%—suffering physical abuse, but also a rate of 2.5% for financial exploitation, which may be the most common form of abuse. Another study found that individuals ages 65 and older make up approximately 30% of all scam victims (Davis, 1993), although in 2015 they comprise only 14.5% of the total population. Financial exploitation and fraud have become such serious issues in the 21st century that in 2009 the federal government established the Financial Fraud Enforcement Task Force (n.d.).

Because of the assumption that older adults have nest eggs set aside for retirement, they are tempting targets for swindlers (Sharpe, 2004). Women, especially the newly widowed, are among the most vulnerable because of the assumption that they may never have entered the workforce, balanced a checkbook, or paid a bill. Lonely and frightened, the new widow sometimes trusts too quickly someone who offers to handle her finances. But clearly older women are not the only victims of crime in later life—remember Bert’s involvement with Shawn’s vitamin business. Scams may involve real estate, stocks, mutual funds, or business investments. Is Shawn’s vitamin business like this, or is it just an investment with some risk? Strangers may perpetrate these scams, but opportunities for exploitation are also found closer to home. Defining exploitation is not always easy. For example, in many cultures, older people share their financial assets with younger people in the family. But loved ones can exert emotional pressure that may be just as detrimental to the older person’s interests as the deliberate manipulation of strangers and acquaintances. Because abusers are often dependent on their older victims for financial support, exploitation can

Exhibit 25  Percentage of the Older Population That Is Female, by Age for the United States, 2010, 2030, and 2050
be linked to verbal or physical abuse. We saw the slippery slope toward exploitation in Bert’s case. But if a presumed victim doesn’t report financial exploitation, then how can one prove a crime was committed? Are we justified in interfering for a person’s own good? How do we go about determining what a person’s “own good” actually might be? These questions underscore just how difficult it is to prevent financial abuse and exploitation of older adults (Jackson & Hafemeister, 2011).

**URBAN LEGENDS OF AGING**

“Older people are more likely to be victims of crime.”

According to Justice Department data and the FBI, older people are less likely to be crime victims than any other age group in the population. However, they’re more afraid of crime, perhaps because they watch more television than other age groups. Older people should probably be more afraid of falling, since falls injure more seniors than crime does.

**GLOBAL PERSPECTIVE**

**Ponzi Schemes Around the World**

A *Ponzi scheme* is a financial scam named for Charles Ponzi, an immigrant to Boston who in the 1920s swindled thousands of people by promising a 40% return on their money. Ponzi simply used money from previous investors to pay new victims, until the chain was eventually broken. Ponzi schemes remain one of the most prevalent consumer frauds. Today’s turbulent stock markets and low interest rates make older people a tempting target for Ponzi schemes and other financial frauds. Older people have even been villains as well as victims: 81-year-old John Heath was sentenced to 28 years in prison for promoting a $190 million Ponzi scheme.

Ponzi schemes are found all over the world. Ponzi himself was an Italian immigrant who began his fraud career with financial elder abuse in Montreal, Canada. International financial fraud today is a huge business, familiar to anyone who has ever received e-mail messages from Nigeria promising huge investment rewards. One of the biggest frauds occurred in Albania in the 1990s, when government officials endorsed investment plans that eventually attracted two thirds of the Albanian population. The plans turned out to be Ponzi schemes that bilked investors out of $1.2 billion until the government stepped in to stop protests and a civil upheaval that claimed 2,000 lives.

According to U.S. postal inspectors, older people are among the biggest victims of financial fraud, including Ponzi schemes as well as chain letters, illegal contests, phony billing scams, and foreign lotteries. Homebound elders constantly receive solicitations by mail as well as from telemarketers. This sad story raises again the challenge of how to protect people from making bad choices (Lachs & Han, 2015).

How can society and loved ones intervene to protect an older person who seems incapable of functioning safely or who has been targeted as a victim by exploiters? Clearly, competing values are at stake here (Cramer & Brady, 2013). One answer is that it is possible to restrict people’s liberty for their own good through legal procedures intended for that purpose (Quinn & Heisler, 2002).

Civil commitment is a legal procedure whereby people can be placed in psychiatric hospitals against their will. The rationale for civil commitment is to diagnose or treat a mental disorder if there is reason to believe a person may be in danger of causing harm to self or others. Civil commitment is an extreme measure causing loss of personal liberty. In previous decades, disoriented older people were often sent against their will to mental hospitals, but today, more guarantees are in place to protect against such actions. In earlier times, “old age” alone might have been a sufficient reason for labeling someone incompetent to make decisions. But today, instead of relying on vague labels like “senility,” we must undertake a formal court proceeding to declare someone mentally incompetent.

When a person is capable of some independence but is unable to manage money or make decisions, another approach is to appoint a guardian or conservator for the incapacitated person’s affairs (Zimny & Grossberg, 1998). Guardianship can take two forms: guardianship of the person, in which the guardian has the power to determine where the older person will live and what treatment or services he or she may receive, and guardianship of the estate, in which the guardian has power to manage property and take over financial affairs (Quinn, 2004). Appointing a guardian is less restrictive than committing someone to a mental hospital, but it still represents a restriction of liberty. Guardianship is overwhelmingly a procedure applied to help older people, as compared with members of other age groups.

Despite the legal safeguards, both civil commitment and guardianship proceedings are viewed by many informed critics as a kind of new paternalism that can be oppressive to older people. Moreover, some studies have shown that depicting people in age-related terms is a common, even routine feature of civil commitment proceedings, and age depictions are rarely challenged. Specifically, behaviors construed as age inappropriate—for example, certain kinds of sexual activity—are frequently cited as grounds for viewing a range of behaviors as symptoms of mental illness (Holstein, 1990). Laws intended to protect older people have vague standards and weak accountability for those who are appointed as guardians or conservators. Civil commitment proceedings may fail to grant older adults an opportunity for a fair hearing, and statutes may not require legal notice, the presence of the older individual at the hearing, or the right to counsel. As well, older adults who are experiencing cumulative disadvantage may be even more vulnerable once they enter into the legal guardianship system (Rosenberg, 2009). The result is that programs intended to protect the old can end up disregarding their rights and causing more harm.

Some of the worst failings of the guardianship system are its disregard for the rights of older adults. The courtroom hearings for incompetency are too often one sided and superficial, and vague laws permit a ruling of incompetency based on flimsy evidence. Moreover, follow-up supervision of guardians who are appointed by the courts remains minimal. Financial incentives make matters worse because guardians and conservators are paid out of the ward’s assets. Appointments to conservatorship jobs may be awarded to politically well-connected lawyers. Once a guardian is appointed, guardianship is rarely revoked before
the death of the ward. Efforts to reform the guardianship system have been frustrated, so advocates today tend to recommend guardianship only as a last resort (Teaster et al., 2010).

In the classic readings that follow, we see some of the dilemmas and controversies that result from efforts to protect older people from vulnerability. The first reading, by Robert N. Brown, emphasizes the basic constitutional right to freedom from restraints. Writing from a civil liberties perspective, Brown raises a basic question: When is government justified in intervening in any of our lives? The excerpt from Terrie T. Wetle and Terry T. Fulmer looks at the ethical dilemmas of how to balance the best interest of people with their right to autonomy. Instead of looking at this question in abstract or societal terms, Wetle and Fulmer stress the social context of families and health professionals who may be obliged to report suspected cases of elder abuse.

On one side, we have the human service professions, but on the other side, we have the legal system. Candace J. Heisler and Mary Joy Quinn describe the presuppositions of the legal system, in particular its adversarial nature. By defining ideas of autonomy, least-restrictive autonomy, and mental competency, the legal system sets the boundaries around the debate about when it is possible to intervene to protect people from their own bad choices. Finally, Dorothy R. Fabian and Eloise Rathbone-McCuan examine the concept of elder self-neglect. In this instance, there may be no outside party engaged in abuse or exploitation. Instead, an older adult may simply insist on living independently under conditions of danger that frustrate our ability to provide protection to vulnerable people.

FOCUS ON PRACTICE

Adult Protective Services

We have seen in Uncle Bert’s case that an older person’s questionable judgment raises a difficult problem: How do we respect an older person’s right to make personal decisions while safeguarding that person from situations of abuse, exploitation, and neglect? There are no easy answers to that question, but practitioners who work with older adults have come up with some practical strategies that deserve attention. One of these is adult protective services, a service program that attempts to balance individual rights with concern for safety and welfare (Teaster, Duke, & Lipke, 2016).

The vast majority of states now have special legislation and social service programs aimed at protecting people like Uncle Bert—that is, people who seem vulnerable to physical or financial abuse and who may be impaired and unable to protect themselves. Laws that protect these vulnerable adults are administered by local departments of aging, departments of social welfare, and even police departments.

Adult protective services workers begin a case by trying to define exactly what they are facing:

- **Is it abuse?** Is someone else in a position to harm a vulnerable adult either physically or psychologically?
- **Is it exploitation?** Is financial abuse, which involves misappropriating another person’s money, a possibility?
- **Is it neglect?** Has a caregiver or someone responsible for a frail elder’s welfare failed to provide minimal support?
Another possibility is self-neglect or endangerment: An individual, entirely independently, may have fallen into a life-threatening situation—for example, wandering around outside in cold weather without adequate clothing or failing to take essential medication. Bert’s case shows how difficult it is to classify a situation as abuse, exploitation, neglect, or endangerment.

What usually happens is that someone in a position to know—a physician, a home care worker, a neighbor, or a friend—reports to authorities that an older person appears to be abused or neglected. Adult protective services then begins a prompt investigation, usually by visiting the home and talking with the people who are involved.

Following this preliminary investigation, adult protective services would prepare a report and decide what to do next. Further fact-finding may be required. For example, it may be necessary to look at financial records or test an individual’s mental status or competency to make decisions. If the facts warrant doing so, the agency will intervene in the case.

Intervention can take a variety of forms, some more aggressive than others. For example, a social worker might try to arrange for home health care or work with the caregivers to make sure that services are delivered smoothly. In Bert’s case, adult protective services would want to make sure that his bruises aren’t the result of harm inflicted by the people who are supposed to care for him. Adult protective services would also look at Bert’s own actions that seem to endanger his welfare, such as wandering in dangerous neighborhoods and engaging in questionable health practices.

This review would try to strike a balance between ensuring the client’s safety and welfare and taking serious account of individual autonomy and quality of life. Striking such a balance is not easy, and adult protective services professionals face a challenging professional task. The agency has to weigh competing interests of family members, older persons, and the values of society as a whole.

In more extreme situations, adult protective services can bring in the police or go to court to obtain a formal order of conservatorship or guardianship. But such serious measures involve risks, which are usually justified only if clear harm is threatened and if a person seems mentally incapable of making decisions about harm and risk. Many cases are borderline, and some individuals simply lead eccentric lifestyles. In such cases, adult protective services workers need great skill and judgment to find a good solution. But the availability of adult protective services gives hope that cases like Uncle Bert’s can be resolved (Ernst et al., 2013).
We know that people, even those without mental or physical limitation, possess differing abilities and have differing needs. Sometimes physical or mental impairments leave people totally unable to manage their personal or financial affairs, as for example a person in a coma. Sometimes impairments affect only part of a person’s ability to care for himself. A person with quadriplegia may be unable to care for himself physically but can direct others in providing care. Some impairments are temporary, such as the mental confusion that may occur as a side effect of medication, while some impairments seem to be permanent, such as the progressive physical and mental deterioration associated with Alzheimer’s disease. Most impairments pose harm only to their victim, who will suffer the effects of not being able to provide for his needs. Some impairments, however, are alleged to pose a risk of harm to others, such as a patient with schizophrenia whom psychiatrists may believe to be nearly certain to physically assault another. In short, there are a variety of physical and mental conditions which may affect, to varying degrees, for a limited or lasting amount of time, a person’s ability to prevent harm to himself or to restrain himself from harming others.

When such conditions exist, and a person no longer can manage to prevent harm to herself or to others, the question is whether, and at what point, the legal system ought to intervene. The means by which legal intervention may be sought, broadly referred to as “protective proceedings,” include such processes as guardianship, conservatorship, and civil commitment. These procedures seek to prevent harm from occurring to an impaired person by legally removing, to one extent or another, the impaired person’s right to make decisions on her own behalf and appointing a surrogate to make decisions in her place. To appreciate the impact of this, some understanding of what “decision making” entails is needed.

Life presents each of us with a constant succession of choices requiring decisions. Most are minor, such as what to wear in the morning, what newspaper to read, or whether to order fish or fowl in a restaurant. Some are major, such as whether to marry, or whether, near the end of one’s life, to move from one’s home into a nursing home, or to undergo painful chemotherapy to fight a terminal cancer. All these decisions, for the purpose of understanding protective proceedings, can be placed into two categories: those that affect financial interests and all others. These latter decisions are considered personal decisions. Financial matters that may be acted on can range from buying a candy bar in a vending machine, to giving a gift to a favorite niece, to selling one’s home to pay for medical care or a college education. Personal matters that may be acted on range from deciding what book to read or television show to watch to deciding where to live, with whom to associate, or whether to have an organ transplant.

When a person loses part or all of the ability to make decisions, it may become necessary for someone else to have the legal authority to act on his or her behalf. If the impaired person had, at an earlier time, entered into an arrangement (such as a power of attorney or a multiple-party bank

account) that would allow another person to act on his behalf, further legal intervention may not be required. If not, however, a protective proceeding may need to be sought. The consequence of such an action is that the impaired person’s right to make independent decisions is diminished or eliminated. The right to make decisions is turned over to the guardian or conservator.

Whether losing one’s right to make decisions and having to abide by the decisions of another is unfair or unjust depends on the circumstances. It may not be a great loss to a person in a coma, who is unaware of any loss of control, to have his choices made by a guardian. It is a good deal less clear what the impact is of making a mentally ill person who makes “not very good” financial choices subject to a style of life dictated by the financial decisions of a court-appointed conservator, on the presumption that the conservator’s decisions will better protect the person’s assets. A person who is not mentally ill but who makes the same “not very good” financial decisions could not be subjected involuntarily to such control. Furthermore, the actual outcome of a decision is never certain. All decisions entail a certain amount of risk; well-thought-out plans often fail, and ill-advised schemes often succeed. There is, in addition, the question of values. What is best for an individual may not be the safest and most long-lasting life, but may include the chance to do what that individual believes is best and most important.

Guardians and conservators are often ignorant of, or fail to heed, the concerns and wishes of their wards. Protective proceedings often give little weight to these concerns. These proceedings seem unable to accommodate the differing natures and degrees of impairments and may not recognize that an impairment which affects one area of a person’s ability to care for himself may not affect other areas. The result is that the law, in seeking to “help,” sometimes takes away rights from those who are merely “different” and not disabled and often fails to respond appropriately to those who need some, but not complete, help.

**What Is the Justification for Government Intervention into Our Lives?**

A general rule of our legal system is that people are allowed to exercise self-determination; people have both the right and responsibility to make their own decisions about how they will live, on what they will spend their money, and how they will spend their days. For the most part, people are free to think, speak, and do as they please without interference from our government. Yet there are limits. Laws limit our freedom by prohibiting us from injuring others or from harming their property. The legal authority for such laws is the “police power” of the state. This power authorizes the state to prescribe activities which are dangerous to others in order to protect society. A person convicted of violating such laws may, for the protection of society, be deprived of his or her freedom. The loss of liberty suffered by persons “civilly committed,” or confined involuntarily in state mental hospitals, is justified in part by the police power of the state. This power authorizes the state to proscribe activities which are dangerous to others in order to protect society. A person convicted of violating such laws may, for the protection of society, be deprived of his or her freedom. The loss of liberty suffered by persons “civilly committed,” or confined involuntarily in state mental hospitals, is justified in part by the police power, inasmuch as such persons are thought to be dangerous to others. Another limitation on individual freedom is the power of the state to protect individuals incapacitated by disease or other causes who consequently cannot care for themselves, their dependents, or their property. This power is called *parens patriae*, or “parenthood of the state.” Unlike police power, which is aimed at protecting others, this power focuses on the incapacitated individual and declares that the state has the responsibility of protecting those who cannot protect themselves. Under the *parens patriae* power, the state has the authority to determine when a person cannot care for him or herself adequately and has the authority to appoint another person, usually called a guardian or conservator, to provide such care.

Because the exercise of police power entails a great loss of liberty (for example, confinement to a prison), procedural protections have long been established to ensure that a person involved in a
criminal proceeding is not mistakenly imprisoned or penalized. Examples of these protections are rights to a lawyer, against self-incrimination, to trial by jury, and to cross-examination of witnesses. Unfortunately, not all of these procedural safeguards are provided to persons threatened with such protective proceedings as civil commitment, guardianship, or conservatorship. The reason is that protective proceedings are, for the most part, theoretically founded on the idea that the intervention will benefit the person, in effect “protect” him from himself. Such benevolent proceedings may be felt to pose no real loss of liberty or harm to a person unable to exercise such rights independently. However, in practice, these proceedings are often brought against persons at least partially if not fully able to exercise their rights and for reasons far from benevolent. The resulting genuine deprivations of liberty and property that occur, such as loss of control of one’s finances or confinement in an institution such as a psychiatric facility or nursing home, suggest there is no justification for failing to offer procedural and substantive safeguards in protective proceedings. Lawmakers should ensure that the most appropriate and least restrictive processes available are used in seeking intervention in an individual’s life.

The application of values and ethical concepts to specific cases of elder mistreatment often engenders ethical dilemmas involving conflict among two or more values or concepts. Several such dilemmas are outlined below including the balancing of individual autonomy with beneficence and paternalism, concerns of confidentiality and legal reporting requirements, the impact of reporting on patient and professional relationships, and the issue of respect for autonomy for patients with diminishing cognitive capacity.

BALANCING PATIENT AUTONOMY AND THE BEST INTERESTS OF PATIENTS

Perhaps the most difficult ethical dilemma for health professionals is the effort to respect the expressed wishes of the patient (autonomy) while protecting the patient from harm (beneficence) (Wetle et al., 1991). It is not uncommon for individuals to behave in ways that place themselves at risk or are personally injurious, or to choose to remain in risky or abusive circumstances. Respecting the autonomous wishes of such an individual may be in direct conflict with the professional’s judgment of what is in the patient’s best interest. On the one hand, the principle of respect for the autonomy of an individual would prevent the health professional from intervening with a service or action that is in opposition to the expressed wishes of a competent patient. On the other hand, health professionals are required, by law, to report cases of suspected elder mistreatment. Moreover, there is also an obligation to determine that the
patient’s refusal of assistance is an autonomous decision, free of coercion or undue duress. These cases are often complicated by questionable decisional capacity or cognitive impairment of the elder patient. Disagreement with a health professional’s judgment or advice is not sufficient evidence to make a determination of decisional incapacity. Certainly, we have moral obligations to protect incompetent elders from incapacitated decision making, but we are also obligated to determine if they are truly incapacitated before intervening against their wishes.

Such a determination requires a formal evaluation of decisional capacity. If the patient is determined to be competent, even if suspected mistreatment is confirmed, the competent patient has the right to refuse interventions.

Confidentiality and Reporting Requirements

Another aspect of patient autonomy is respect for confidentiality. Once again, the elder abuse reporting laws override the obligation for confidentiality under very specific circumstances. Nonetheless, this is not a blanket override, in that such reported information must be handled with extreme care, and information identified in subsequent investigations should be shared only on a “need to know” basis.

Impact of Reporting on Patient/Professional Relationship

Many professionals express justified concern that an elder abuse report and the subsequent investigation will have deleterious effects on their relationships with patients (and patients’ families). Much progress has been made in improving the response system and investigating approaches used to determine whether or not mistreatment has occurred and in planning appropriate interventions. Nonetheless, even the most skilled response to such a report may damage the relationship between professional and patient. Several steps can be taken to reduce negative impacts, including informing the patient that such a report is to be made, describing the process, identifying potential positive outcomes of the process and suggested interventions, working with the family as a unit if possible, and recognizing the needs and concerns of all involved.

Ethical Issues Related to Families and Health Professionals

Family members are often intimately involved in the care of frail elders. Several ethical issues and conflicts relevant to elder mistreatment are faced as health professionals care for the individual patient in the context of family caregiving. These issues include questions regarding just who is the patient, caregiver burden and inadequate family supports, changing dependency relationships and longstanding patterns of family interaction, and ethical approaches to families. Many of these issues are discussed elsewhere in this volume in substantial detail, but are briefly discussed here from the perspective of the health professional.

Who Is the Patient?

It is not uncommon for health professionals to become involved in the treatment of the family as a unit, as well as in care of an individual patient. The burden of caregiving can be substantial, and some cases of elder mistreatment occur when a well-intentioned primary caregiver becomes overwhelmed by caregiving tasks. The health professional faces a particularly thorny dilemma when treating two members of a family as patients and encounters evidence of mistreatment of one by the other (Fulmer, 1991). This raises the question of just who is the primary patient, and how are the professional’s obligations to be balanced among various members of the family. Certainly, there is a first-level responsibility to the patient who appears to have been mistreated but successful
Basic concepts

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It is not unusual for family caregivers to drain all physical and emotional resources before accepting help or assistance. One responsibility of health professionals is to assist caregivers in recognizing the limits of their own health and to promote their well-being by identifying supportive services and encouraging their use and by assisting in balancing caregiving among all available family members. This may in fact have a double protective effect. First, it may prevent the elder abuse or neglect that might have been triggered by caregiver overburden and stress. Second, such interventions may protect the caregiver from the overburdening that also could be considered a form of “caregiver mistreatment” or abuse.

Dependency Relationships in Families Change as One Member Becomes Increasingly Dependent on the Family for Care

The health professional may be unaware of long-standing patterns of interaction among family members. The stresses of family caregiving may exacerbate a relationship that has always been characterized by verbal and physical abuse. In some cases, changing dependency relationships may turn the tables, and the previously abused may become the abuser. Being aware of these patterns and the specific relationship history of caregiver and care receiver may help explain observed dynamics and provide crucial information for developing effective intervention strategies.

Caregiver Burden and Spousal and Intergenerational Responsibilities Involve Differing Personal and Societal Expectations

Society remains unclear as to the reasonable level of caregiving to be expected from a spouse or adult child. It is not unusual for family caregivers to drain all physical and emotional resources before accepting help or assistance. One responsibility of health professionals is to assist caregivers in recognizing the limits of their own health and to promote their well-being by identifying supportive services and encouraging their use and by assisting in balancing caregiving among all available family members. This may in fact have a double protective effect. First, it may prevent the elder abuse or neglect that might have been triggered by caregiver overburden and stress. Second, such interventions may protect the caregiver from the overburdening that also could be considered a form of “caregiver mistreatment” or abuse.

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A Legal Perspective on Elder Abuse

Candace J. Heisler and Mary Joy Quinn

Most practitioners working with older adults have had limited experience with the American legal system. As a result, it is underutilized in the prevention and resolution of elder mistreatment. . . .

Goals of the Legal System

The civil and criminal legal systems approach the prevention and resolution of elder mistreatment approaches include offering information and services to all involved parties.
matters with common goals and certain rules that govern their handling. The goals of the legal response to elder mistreatment are to: (1) Stop the unlawful, improper, or exploitive conduct that is being inflicted on the victim; (2) Protect the victim and society from the perpetrator and further inappropriate or illegal acts; (3) Hold the perpetrator accountable for the conduct and communicate a message that the behavior is unacceptable and exceeds societal norms; (4) Rehabilitate the offender, if possible; and (5) Make the victim whole by ordering restitution and/or the return of property as well as the payment of expenses incurred by the victim as a result of the perpetrator’s conduct.1 The two parts of the legal system also seek to act in ways that create the least disruption or invasion into the victim’s life; that take into account that person’s individual situation, competency, wishes, and desires; and that keep the situation from becoming worse.

The legal system is adversarial in nature. In the clash between the parties in a search for the truth, the legal system mandates roles for the participants. On the civil side, the person who files the lawsuit is termed the plaintiff and that person must meet one of the two legal burdens previously described in order to prevail. Because the lawsuit generally concerns the interaction of two or more parties, the parties themselves retain control over the case. The plaintiff and the defendant can settle the case, come to agreements, and otherwise direct what takes place. Where guardianships are concerned, the person filing the case is typically termed the petitioner because traditionally, guardianship hearings have not been adversarial. Rather, there has been an assumption that the petitioner is acting on behalf of an older adult who needs help. Traditional views are giving way to many system reforms as it is realized that sometimes persons seeking guardianship are acting in their own interests rather than to assist an elder in need. The result is that guardianship proceedings are becoming more complex and, at times, adversarial in nature. Legal rights of proposed wards are protected to a greater degree than occurred previously.

**Ethical Issues**

The ethical issues most apparent in legal proceedings with elder mistreatment are (1) promotion of autonomy and (2) least restrictive alternative. Ethical dilemmas arise when evaluating these issues in light of an older adult’s mental competency.

**Autonomy**

American legal and ethical values place a high priority on autonomy. The issue is self-governance: “being one’s own person, without constraint either by another’s action or by psychological or physical limitations.”2 The high value placed on autonomy is reflected in the Constitution and the professional ethical protocols of the medical, legal, and nursing professions.3 Autonomy may be an idealized notion given the very real interdependence most elders have within their families and their communities and given the reality of high levels of impairment in old age.4

The issue of autonomy is always present whether the older adult is in the civil or the criminal justice system. In the criminal justice system, the issue of autonomy comes into play when the elder is informed and consulted about the various options available to keep him or her safe and when the sentencing of the offender is under consideration. It is not a victim’s responsibility to determine if criminal charges will be brought against an offender and in many jurisdictions, victims are not asked to “press charges.” The prosecuting attorney, as the state’s representative, makes that decision in order to communicate the message that the conduct is criminal, not simply a “private matter,” and to ensure that the victim is protected, rather than manipulated, exploited, or threatened.

In guardianship matters, autonomy is the main issue when an adult is thought to be incapable of
managing his or her affairs, whether due to abuse or neglect by self or others. In guardianship, decision making is placed in the hands of surrogates. With changes in state laws and the dissemination of current gerontological thought, courts now carefully consider autonomy and the wishes of the elder as expressed in the past, the present, and for the future. Forward-looking courts seriously consider these expressions in their deliberations, regardless of the mental status of the older adult.

Ethical practice requires that practitioners are careful not to err on the side of failing to take action to protect an elder. Blind adherence to the concept of autonomy can lead to resolutions that fail to ask even the most basic questions and can result in the abandonment or death of a client who declines the first offer of help or who has an unpleasant personality or is “difficult.”

**Least Restrictive Alternative**

The concept of the least restrictive alternative, a legal doctrine first articulated in the field of mental health, has gained wide acceptance among courts and service professionals. It creates an ethical duty for practitioners to fashion individualized solutions that are least intrusive upon their client’s personal freedom. The concept applies to the personal and the environmental care of the elder and the handling of material resources. It recognizes that elders may have capacities in some areas and lack capacity in others. Ideally, the more restrictive the option, the greater the due process protections and the opportunities for the individual to object and state preferences. The doctrine is primarily civil in nature, though on occasion it is applied in criminal matters, particularly in the placement of persons found to be criminally insane.

In civil law, legal options begin with the client handling [his or her] own affairs and then move up the ladder to more restrictive options in the following manner: client signs name to checks but someone else fills out the checks, direct deposit to bank accounts, representative payee arrangements for certain checks, joint tenancy on bank accounts and/or real property, trusts, the various powers of attorney, protective orders (for placement or medical treatment), guardianship of estate, and, lastly, involuntary placement in a locked mental health facility.

Legal alternatives to guardianship are used more frequently, especially since 1987 when the Associated Press conducted a nationwide investigation into the guardianship system and found it woefully lacking in protections for frail elders. In most cases, a neutral person never spoke to elders or advised them of their legal rights despite the fact that a guardianship often deprives them of many rights such as the rights to vote, to make a will, to select a physician, or to control finances. Following that investigation, most states amended their guardianship laws. Also as a result of the investigation, practitioners began relying on less restrictive legal options, sometimes without fully considering their benefits and burdens. For instance, there has been heavy reliance on powers of attorney with little understanding that there is no bonding, no notice to other relatives, no monitoring by a third party, and no way to regain misappropriated or mishandled assets short of a civil lawsuit. There has also been reliance on trusts that may be beneficial financially in some situations but make no provisions for personal care or abusive trustees. Additionally, individuals who become trustees or attorneys-in-fact seldom understand what is required and as a result, they assume responsibilities that they are not prepared to handle. Ethical practice requires that practitioners in the position of recommending legal options have basic knowledge of the benefits and burdens of each legal option and mandates that practitioners fully discuss all available options with the client.

The concept of least restrictive alternative is not easily transported to the criminal justice system. It is not a guiding principle for the criminal system though most courts decide sentences by balancing what a perpetrator did with available sentencing alternatives while attempting to protect the public, hold the offender accountable,
and protect the victim and society at large. The concept of least restrictive alternative can be seen in criminal matters that are relatively minor and may have elements which are both civil and criminal in nature. Interventions may begin in the civil arena and move to the criminal side if the offender does not comply. For instance, the offender may first be warned and urged to make changes, then officially admonished, then cited, and eventually arrested. This process is sometimes used in situations involving public nuisances or neighborhood disputes. Finally, the least restrictive alternative approach is applied in the criminal justice context with those found criminally insane. Persons are placed in facilities according to the amount of treatment and control they need and the degree of protection the community requires.

**Competency**

The issue of competence is critical in the legal context. It determines whether a witness will be allowed to testify in a criminal case, if a guardianship will be imposed, and if a lawsuit is “winnable” based on the allegations and evidence a victim produces. And yet, the term is as poorly understood in legal circles as it is in mental health and clinical gerontological settings. Marin et al. note ... that there is growing recognition of the difference between legal competence and clinical competence. All adults are thought to be legally competent until a court of law rules otherwise. This means they can execute legal documents, make medical decisions, decide where to live, and in general, have full control of their lives. Clinical competence relies on observations of health and social services practitioners. It is task and time specific. It is interesting to note that recent guardianship reform laws have tended to incorporate concepts of clinical competence into the law.

Over the years, competency has been variously measured by old age, the quality of decision making, medical or psychiatric diagnosis, risk of impoverishment through heedless spending, and physical endangerment. In truth, the search for a commonly accepted definition of competence can be likened to the search for the Holy Grail. The journey is ongoing but as yet there is no mutually agreed upon conclusion. Each discipline functions with its own definition. For instance, the legal profession focuses on what an elder is incapable of doing while psychology looks at what the elder is capable of doing.

Many state laws provide that a guardianship can be imposed on an individual who is “subject to undue influence,” but that concept does not appear in the medical or psychiatric reports upon which criminal prosecutors and civil attorneys must rely. It does not appear to be a concept that is familiar to practitioners outside the legal field. Undue influence situations can occur even when an elder is alert, oriented, and capable of carrying out activities of daily living. Undue influence has been defined as the substitution of one person’s will for the true desires of another. It can be accompanied by fraud, duress, threats, or the application of various types of pressure on susceptible persons including frail elders.

Current trends conceptualize “competency” in ways other than simply evaluating the quality of the elder’s decision making. There is growing reliance on a constellation of factors to determine competency. There is more focus on what the older adult actually does to take care of the needs of daily living including the management of material assets. There is consideration of the elder’s past decision making. For example, was the elder in the habit of giving large sums of money to perfect strangers or is this new behavior? Medical and psychiatric diagnoses offer valuable information as to conditions that impinge on mental functioning and are able, with some measure of accuracy, to predict the course of a given condition. There is recognition that mental and physical functioning is subject to a variety of factors such as nutritional status, the presence of mental illness such as clinical depression, the time of day, isolation, grief
states, substance or medication intake, relationship status, and self-esteem. There is also recognition that “competence” is dependent on the types of personal and environmental support an older adult may be receiving.\(^{12}\)

Given all these complexities, it is understandable that there is no single tool to determine competency. Nevertheless, practitioners working with frail older adults who are the victims of elder abuse and/or neglect must try to determine if their client is “competent,” often in order to take decision making away for what are usually good and benevolent reasons.\(^{13}\) In general, practitioners look for two elements when assessing competency: (1) Does the individual have the capacity to assimilate the relevant facts? and (2) Can the person appreciate or rationally understand his or her own situation as it relates to the facts at hand? Relevant questions include: Can the person make and express choices regarding his or her life? Are the outcomes of these choices “reasonable”? Are the choices based on “rational” reasons? Does the person understand the personal implication of the choices made?\(^{14}\)

The reality is that dealing with competency is less about creating the perfect definition and more about working with the characteristics of the individual older adult.\(^{15}\) Practitioners must deal with the definitions that are set forth in their respective laws and disciplines while understanding the everyday realities of “competence.” For instance, the criminal prosecutor or civil attorney may realize that the elder victim is less cognitively clear in the afternoon and therefore will attempt to have him or her testify in the morning. Those working within civil and criminal courts may attempt to ensure that judges who hear elder mistreatment cases are familiar with their special dynamics. In the absence of valid tools to accurately measure the various features of competence, we must rely on a variety of pieces of knowledge about elders and the conditions that affect them. Ethical practice demands no less.

### Notes


6. See, e.g., Calif. Penal Code Sections 1026 et seq.

7. Quinn, M. J., Tomita, S. K., Elder Abuse and Neglect: Causes, Diagnosis, and Intervention Strategies, supra.


12. Willis, S. L., supra.


READING 29

Elder Self-Neglect
A Blurred Concept

Dorothy R. Fabian and Eloise Rathbone-McCuan

Self-neglect has been emerging poignantly as one of the many troublesome problems that beset the elderly. It is a source of anxiety and frustration for practitioners, family members, and the community because self-neglecting elders may present themselves in antisocial and life-threatening situations. That is because self-neglect is frequently manifest by disregard of the needs of both the self and the environment. Usually, self-neglect results from physical and/or mental impairments that reduce the elder’s ability to perform essential life tasks. There may be no shame about the situation, and outside help may be refused or passively sabotaged.

Self-Neglect in the Literature

Self-neglect is probably not a new phenomenon. Isolated, frequently unkempt, and often eccentric individuals such as hermits, witches, tramps, and recluses have long been depicted in the social history, literature, folklore, and opera of Western society. These were the early sources of cultural stereotypes depicting extreme examples of self-neglecters. Often arousing fear, discomfort, and disgust, some of these men and women were seen as mentally ill; some were expected to be able to call on fearful supernatural powers; some were thought to hoard treasure. All were considered strange and lived on the social, if not the physical, periphery of their communities. The local populace tended to subject such individuals to jeers, taunts, beatings, and ostracism.

Imprisonment, banishment, or violent death at times followed attention by authorities.

The stereotyping of elderly self-neglecters continues through mass media efforts to keep the U.S. homeless population viable as a news-worthy phenomenon. An increasing amount of
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Contemporary medical and psychiatric literature has addressed gross neglect as a manifestation of individual dysfunction even though it is not clear that the rate and severity of self-neglect in the aging population have increased. Clinical case studies and reports of small samples attempt to verify that self-neglecters become embroiled with the police, wander into emergency rooms, and plague social service agencies. Lurid published accounts lead the public to conclude that high-cost care to improve the condition of these persons provides no long-term benefits and that many of those who do receive community resources will eventually die in very deteriorated conditions.

In attempts to understand self-neglect, certain observers noted an age-related dimension. Macmillan and Shaw (1966) used the senile breakdown syndrome to describe persons failing to maintain levels of cleanliness that the community found acceptable:

The usual picture is that of an old woman living alone, though men and married couples suffering from the condition are also found. She, her garments, her possessions, and her house are filthy. She may be verminous and there may be feces and pools of urine on the floor. These people are often tolerated for years by the neighbors, who may suddenly decide that they cannot stand this state of affairs any longer and report the case to various organizations, such as the police or the health department. (p. 1032)

Clark, Mankikar, and Gray (1975), referring to the fourth-century Greek philosopher Diogenes, who reportedly admired lack of shame, outspokenness, and contempt for social organization, suggested the phrase “Diogenes Syndrome” to characterize elderly patients who appeared filthy and unkempt, whose homes were dirty and untidy and usually full of hoarded rubbish, but who showed no shame for these circumstances. Although not necessarily poor or in substandard housing, these self-neglecting individuals were usually known to social service agencies, whose efforts were frequently resisted.

The term “Diogenes Syndrome” became a stereotype for self-neglecting elders perceived as grossly neglectful of their person and the environment, who displayed not only lack of shame but also contempt for, or at least lack of interest in, the recommendations of neighbors, family members, health providers, or the community at large. The Diogenes Syndrome is used to describe patients in at least one nursing care study (Cornwall, 1981) as well as in a paper on psychotic disturbances (Klosterkotter and Peters, 1985). It is also referred to in a study of the social breakdown syndrome in community-dwelling elderly (Radebaugh, Hooper, and Gruenberg, 1987).

Conceptual Ambiguities

Insights into how to treat or resolve self-neglect among the elderly are subject to as much ambiguity as are the diverse explanations of causality. Cybulska and Rucinski (1986) comment:

Regrettably, when one is faced with a clinical decision whether to intervene or not, the scanty research, medical textbooks, and professional training offer little help. If a crisis occurs in the community, it is often difficult to determine whether the neglect was a result of a consciously determined free choice, some deeply rooted unconscious factors, helplessness, or mental or physical illness. (p. 25)

This ambiguity and the contradictions that surround the problem of self-neglect among elderly persons result in decisions regarding intervention that may become mired in a morass of ethical dilemmas. The desire to guarantee a client’s personal safety is often pitted against that client’s right to self-determination. The struggle to provide some responsible intervention may be experienced at several levels. The first is between the practitioner and the would-be...
client who is not amenable to assistance but is in rapid decline or dangerous circumstances that can be attributed to self-neglect. Also, the practitioner’s effort to obtain access to what the client needs may be frustrated because agencies and organizations controlling resources have not responded in accordance with client need. A third issue may involve matters of jurisdiction over a client, the resources needed by the client, or a combination of the two.

Important ethical questions seem to surface at almost every turn when practitioners are attempting to work with self-neglect problems. Debates about lifestyle and judgments made by others do not entitle society to develop a general policy of pitchforking people into institutional tidiness (Roe, 1987). Even the mentally ill have an increasing amount of protection from those who would help out of concern and from others who would act out of a blatant or subtle desire to control behavior that is considered unacceptable by some sector of the community.

The field of aging needs to consider what guidelines are appropriate to direct intervention around matters of elder self-neglect. Part of that process will involve helping clinicians to gain the expertise to engage the self-neglecting elderly in a process that respects client autonomy to make a choice even if that choice is counter to clinical opinion, that engages clients in a process of decision making rather than mere debate over the decision, that helps clients accomplish steps toward health and well-being, and that facilitates the best outcomes of those decisions, once made and implemented.

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Inheritance in an Aging Society

How important to American families is the transfer of wealth from one generation to another? The question is not just one for individual families; it is part of a broader issue about the role of inheritance in society. In previous times, inheritance was of interest mainly to the wealthy, but inheritance now commands attention from more and more middle-class people. A rise in real estate values of homes bought in the 1950s or 1960s, combined with high stock market values in the 1990s, has made many older parents more wealthy than they, or their children, ever imagined they would be.

Inheritance can permit adult children of today’s retirees to put their own children through college, start a business, or prepare for their own retirement. Laws curbing Medicaid spend down and the growth of private long-term-care insurance are two signs of concern around inheritance issues. Much of the practice of elder law attorneys is concerned with inheritance in one way or another. Inheritance plays a large role in late-life financial planning, and it can have a major impact on family wealth, which is partly why guardianship law came into being. It is estimated that transfers of assets account for at least 20% of total family net worth (Gale & Scholz, 1994). There has been much speculation about whether today’s baby boomers will inherit substantial wealth from their elders. A MetLife study conducted in 2013 revealed that of the oldest boomers interviewed, 33% had received an inheritance from their parents. But future patterns remain to be seen as the boomers continue to age into later life, and in any case, inheritance is unevenly distributed across the population (Gokhale & Kotlikoff, 2000).

Although a majority of Americans do not have wills, those who do are most likely to be older: About 70% of Americans over the age of 70 do, and the proportion who have wills rises with household income and assets as well as educational background (O’Conner, 1996). Eighty-nine percent of these wills provide for family members apart from the spouse, mostly leaving property to children.

Gerontologists have recently identified how important it is to older people to leave some kind of legacy to their children, but they note that the meaning of legacy has been changing in recent years (Kane, 1996). In fact, some analysts point to what they call an inheritance revolution. Parents transfer wealth to their children by paying for their education, rather than transferring property like the family farm. As a result, their children may not expect to receive an inheritance upon their parents’ death. In addition, with people living longer, more of their assets may be consumed—for example, by long-term-care expenditures. Other elders may take the view that surviving generations do not have a valid claim on assets in the first place: A popular bumper sticker reads, “I’m spending my children’s inheritance.” Still others take the view of wealthy financier Warren Buffett, who has limited what his own children will receive because he feels that inheritance can have a negative influence.
Questions about inheritance are always related to the distribution of wealth and income across the broader population. In general, wealth is unequally distributed in the United States, and this inequality has increased in recent years. More than half of all wealth is held by those in the top tenth of the income distribution, and most of this wealth is held by the richest 1%. Estate taxes, which would tend to even the score, amount to less than 1% of federal tax receipts. More than half of the states have some form of estate or inheritance tax, but many exempt transfers to surviving spouses. The federal estate tax has a $1 million exemption ($2 million for couples), and as a result, only around 2% of estates are susceptible to federal taxation (Mieskiel, 1996). Recent efforts to raise this exemption threshold even higher make it likely that inheritance and intergenerational transfers will become an even more important part of family life in years to come.

Questions for Writing, Reflection, and Debate

1. List the things that define quality of life—what makes life worth living for you personally. Then rank the terms on your list with the most important first. Now try to imagine yourself as an older person in your 80s living alone. List the things that would constitute quality of life for you at that age. Is your second list the same as the first one, or is it different? What conclusions do you draw from this fact?

2. When it comes to deciding on matters of personal liberty, the law is supposed to treat adults alike regardless of age: There are no exceptions based on age or personal circumstance. The only basis for civil commitment is the combination of danger plus mental incapacity. Do you think the law should be rewritten to make an exception for frail older people who are vulnerable to mistreatment? Write a newspaper editorial to make your case one way or the other.

3. Suppose that one of Uncle Bert’s nephews or his niece was spending many hours each week doing errands for and taking care of him. Should such caregiving be a basis for expecting some share of an inheritance? Defend your opinion.

4. Imagine that you are the social worker from the welfare department who knocked on Uncle Bert’s door and was turned away. Write a memorandum to your supervisor stating what you believe should be done next, using all the facts you know about issues of elder abuse. What is the biggest risk you can think of if your boss agrees and you do what you’ve recommended?

5. Imagine you are a local police precinct captain in a city that has recently had some much-publicized crimes against older people. You are getting ready to give a speech to the local Kiwanis club about the police department’s plans for responding to the situation. What facts about crime and older adults would you cite in preparing your speech?

6. Visit the website for the National Center on Elder Abuse: http://www.ncea.aoa.gov/. How would you assess the reliability of the statistics cited on this website? Give some reasons that the number of victims of elder abuse in the United States could be much smaller than the statistics cited here. Can you think of reasons that the number of victims of elder abuse could be much larger than the statistics cited here?

7. Financial exploitation of elders is becoming a much bigger problem today. Visit the website for the National Consumers League Fraud Center: www.fraud.org. What frauds and scams are most likely to target elders in the future as the older population becomes more familiar with computers?
Suggested Readings


Student Study Site

Visit the Student Study Site at [http://study.sagepub.com/moody9e](http://study.sagepub.com/moody9e) for these additional learning tools:

- Flash cards
- Web quizzes
- Chapter outlines
- SAGE journal articles
- Web resources
- Video and audio resources
The play *Whose Life Is It Anyway?* tells the story of a patient suffering from paralysis and confined to bed (Clark, 1978). In the play, the patient, played by Mary Tyler Moore, engages in a spirited debate with her doctor, asking for help in ending her life. She is no longer able to live as the kind of person she has always known herself to be, so the drama of the play centers on the question: What to do?

Increasingly, this kind of question is asked not about people like the character in the play, but about their grandparents. More than two thirds of all deaths in the United States occur among people ages 65 and older. More and more, the timing of death is not an event that happens according to nature, but instead is a decision made by human beings.

End-of-life decisions are rapidly becoming our choice to make, regardless of whether we want to make them. Medical advances force us to make decisions unforeseen just a few decades ago. For example, in times past, a person who was unable to breathe without help would die within minutes. Today, mechanically assisted respiration or artificial nutrition and hydration (tube feeding) can sometimes sustain life for years. But medical technology that is a benefit to some can become a burden to others. The decision, in any event, is not easily avoided.

How we understand the decisions to be made will help shape the kind of decisions we make. Consider the moral problem of *euthanasia*, a term that originally came from ancient Greek, meaning simply a “good death.” The question put forth by the play *Whose Life Is It Anyway?* is whether a doctor should help the patient end her life. Will the doctor, in other words, engage in active euthanasia—sometimes called mercy killing? The term active euthanasia is used here to denote some deliberate intervention to end the patient’s life, such as giving a fatal dose of painkilling medication. Passive euthanasia, by contrast, means not doing something, such as withdrawing life-supporting therapy, with the result that the patient dies (Dworkin, Frey, & Bok, 1998). Finally, there is the option of assisted suicide, in which a doctor or family member actively provides the means or carries out the instructions required for an individual to end his or her life.
People interpret the morality of these acts or omissions in different ways. Some answers depend on how we ask the question and the terms that we use. Most people sharply condemn involuntary euthanasia—that is, killing someone without his or her consent because one believes that person would be better off dead. But there is much more controversy about voluntary euthanasia. Moreover, some critics wonder whether there really is a valid ethical distinction between active and passive euthanasia. Others ask whether there is any difference between direct killing and assisting someone who takes his or her own life. These issues have been debated intensely in years past (Pappas, 2012), and the issues will continue to be debated in years to come (Gorsuch, 2009).

These questions are not abstract or hypothetical at the moment when it is time to terminate life-sustaining treatment (Berlinger, Jennings, & Wolf, 2013). Does it make any difference whether we withhold a treatment from the beginning or withdraw that treatment once it has already started—for example, “pulling the plug” in the case of a mechanical respirator? Then again, what really counts as treatment anyway? For instance, would food and water be considered a treatment in the same way that administering antibiotics is a treatment?

These are some of the ethical issues involved in end-of-life decisions. As the timing of death has been displaced more and more in later life, older people obviously have a vital interest in this debate. On one side are those who argue that the right to self-determination means patients should have the means to end their lives at a time of their own choosing. On the other side are those who warn that the right to suicide or euthanasia runs grave moral risks. For example, should we encourage depressed older people to end their lives instead of changing the conditions that gave rise to the problem?

**Depression and Suicide**

Depression is certainly an issue that needs consideration for people who express a wish to die (Steinberg & Youngner, 1998). Psychologists have identified a number of common predictors of suicide: intolerable psychological pain and frustration, a feeling of hopelessness or helplessness, and communicating the intent to kill oneself (Osgood, 1992). Although depression is not a normal part of the aging process, old age is not a time of happiness for everyone. According to the National Institute of Mental Health (2010), “Estimates of major depression in older people living in the community range from less than 1% to about 5%, but [depression] rises to 13.5% in those who require home healthcare and to 11.5% in elderly hospital patients. A much larger percentage of older adults may experience periods of depression that aren’t severe enough to receive a medical diagnosis. And there are differences in the rates of diagnosis and treatment for community-dwelling older adults who are members of ethnic minority groups (Akincigil et al., 2012). But what exactly does depression mean? Clinical depression is different from the “down” state that is a common, but usually temporary, response to setbacks. Depression following bereavement, and depression among residents of nursing homes may be a reaction to the fact that it is difficult to “start over” in later life.

Clinical depression remains the most important cause of suicide among the old (Blazer, 2001; Sachs-Ericsson, Van Order, & Zarit, 2016). But depression is rarely the result of social isolation or withdrawal alone. In fact, most older suicide victims either live with family or are in contact with family and friends. Nearly three quarters of older people who commit
suicide have had a recent visit to their primary care provider, but rarely has any older person who committed suicide received mental health services, specifically treatment for depression (Ellison & Verma, 2003).

Of all age groups, older people are most at risk for suicide (National Institute of Mental Health, 2010). Suicide rates do not rise with increasing age for women, but they do go up with advancing age for men. Older people make up around 14.5% of the U.S. population but account for 15.7% of all suicides, according to the American Association of Suicidology (2009). Epidemiological studies estimate the rate of major depression at under 1% in the population ages 65 and older. But at least a quarter of older people living in the community show significant depressive symptoms that have a functional impact on their lives. For older people who are isolated, however, lack of social support can make it difficult for them to cope with depression and overcome it.

Depression is difficult to diagnose because it can manifest itself in a variety of symptoms. Older adults may report insomnia, fatigue, inability to concentrate, anxiety, and other physical or emotional discomforts. Depression is also difficult to diagnose among older adults because its expressions are transient or appear along with other problems, such as dementia. In addition, some symptoms of depression can be confused with changes associated with normal aging, such as withdrawal from activities. Finally, late-onset depression may differ from depressive disorders that begin earlier in adulthood (Roose & Sackeim, 2004).

Psychiatrists use the term clinical depression to describe the presence of five or more symptoms, such as loss of appetite, sleep disturbance, and so on. But late-life depression might better be viewed along a continuum, with an individual’s place on the continuum determined by the number of symptoms experienced during a defined period of time (George, 2010). Older adults report higher levels of depressive symptoms than younger adults, but they are less likely to meet all the criteria for diagnosis of clinical depression. Age by itself is not necessarily a risk factor for depression, and depression is not necessarily more common among the aged than among younger adults.

The majority of older people do not feel sad or unhappy most of the time. Contrary to stereotype, a third of respondents said old age was the happiest period of their lives. In short, although there are differences between older individuals and a wide variety of experiences, the stereotype of old-age misery is wrong.

The psychological problem is that multiple losses and the expectation of further losses can be damaging to self-esteem and can weaken healthy psychological defense mechanisms (Vaillant, 2003). Denial may no longer be possible when an older person faces deterioration and dependency in the course of illness. In such cases, it is not easy to say whether an older person’s rejection of lifesaving treatment, for instance, represents an informed choice to be respected or instead is a sign that the patient needs help for a depressive disorder.

Depressed older adults do not differ from nondepressed elders in the number and types of medical interventions they want when their overall outlook is poor. Counterintuitively, depressed patients are more likely to refuse procedures in situations where the medical prognosis is actually good. The factor that explains most of the difference may be not clinical depression but broader quality of life, which a clinical depression diagnosis may not capture (Lee & Ganzini, 1992).

A serious ethical dilemma arises for older people and their families. Many doctors are intensely committed to keeping patients alive and may therefore doubt that anyone who rejects a life-sustaining treatment can be fully rational. The mere fact of deciding not to
continue living becomes “proof” of irrationality. But this attitude of “treatment at all costs” fails to take seriously the possibility that some people in the last stage of life may decide that they simply have lived long enough. Should we therefore fail to respect their decisions?

The dilemma was clear in the case of Theresa Leguerrier, a resident in the Good Samaritan Nursing Home in upstate New York. She was in her 80s but was not suffering from any serious medical problems. One day, she began to refuse food and water, expressing a wish to die of starvation. Staff in the nursing home were divided in their opinion about what to do. The nursing home administration claimed that, by refusing food, a resident might make the home vulnerable to legal penalty for assisting suicide. Against this view, a physician and a social worker involved in the case maintained that Leguerrier was rational and competent to make her own decision in the matter. The nursing home petitioned a court to institute artificial feeding, but the court eventually agreed with the patient’s right to refuse treatment in this case.

Some patients who reject a treatment or behave in another way that puts life at risk, such as refusing food, may be suffering from a treatable depressive disorder. They simply lack enough “tender loving care.” Surveys of nursing home residents, for example, suggest that depression is widespread among residents. To adopt a laissez-faire attitude—“Well, it’s their choice to make”—fails to take seriously the way depressive disorders can impair judgment. Failing to diagnose and treat late-life depression could consign untold numbers of older people to self-imposed death by neglect under the label of self-determination, but regarding anyone who refuses treatment as suffering from mental illness is disrespectful of the patient’s autonomy. A difficult dilemma, indeed.
The "RIGHT TO DIE"

Widespread public discussion of the ethics of death and dying began during the late 1960s (Filene, 1998). The first stimulus to this debate was the problem of brain death, a condition in which a critical part of the brain loses its ability to function. When mechanical respirators were developed that could be used to keep patients in this condition alive, states passed laws defining when death could be said to occur under these conditions. But defining the moment of death was not as vexing a problem as resolving the ethical dilemmas around end-of-life choices.

The first major “right-to-die” case was that of Karen Ann Quinlan (In re Quinlan, 1976). The patient, who was 21 years old at the time, was in a coma. Her family asked the court’s permission to discontinue the use of a mechanical respirator, which they termed an “extraordinary means” of sustaining life. Upon appeal, the New Jersey Supreme Court ruled that there was a constitutional “right to privacy” to permit withholding or withdrawing life-sustaining treatment. Quinlan was then removed from the ventilator and brought to a nursing home, where she remained for 9 years, sustained by feeding tubes and antibiotics until her death in 1985.

The Quinlan case was not an isolated incident, but it stimulated new legislation. The first important “right-to-die” law passed was the California Natural Death Act (1976). Since then, other states have been the scene of both legislation and court decisions that pushed far beyond the California law.

Under widely recognized principles of common law in the United States, people have a basic right to accept or reject medical treatment and therefore a right to refuse treatment. This principle of autonomy remains the foundation of legal and ethical thinking about end-of-life decisions. Many state courts, along with the U.S. Supreme Court, have found that a constitutional right to refuse treatment can be exercised by another person on behalf of someone who has been deemed legally incompetent. Where no family member is present, courts have relied on a guardian ad litem: a designated spokesperson who represents the interests of the incapacitated person and reports to the court.

Courts have relied on two kinds of standards to determine when it is proper to withhold or withdraw life-sustaining treatment from patients deemed legally incompetent: the standard of substituted judgment (What would this patient have wanted under these conditions?) and the best-interest standard (What is the balance of benefits and burdens that a “reasonable person” might want under these conditions?). Some evidence suggests that each of these approaches appeals to different groups of older persons (Moore et al., 2003).

The American Medical Association (AMA, 2011) issued a statement approving, in appropriate cases, the removal or withholding of life-prolonging medical treatment. The AMA stated that discontinuing all means of life-prolonging treatment was “not unethical” even if the patient’s condition was not terminal but the patient was instead in an irreversible coma. This view echoed the finding of some courts.

Typical of a whole range of end-of-life decisions in later life was the 1985 case of Claire Conroy, age 84, a nursing home resident (In re Conroy, 1985). Her nephew, appointed as her guardian, asked a New Jersey court for permission to remove a nasogastric tube. The trial court first granted permission on the grounds that life for the patient had become too great a burden. But the New Jersey Supreme Court, reviewing the Conroy case, rejected that reasoning and
instead defined a range of procedures incorporating tests of substituted judgment and the patient’s best interest. Another case of this kind was that of Earle Spring, age 77 and suffering from both dementia and kidney failure. The Supreme Judicial Court in Massachusetts ruled that court approval is not necessarily required before withholding treatment from a patient deemed incompetent to make his or her own decisions (In re Earle Spring, 1980).

But decisions in one state court may not be consistent with those in other states. In the Mary O’Connor case (In re Westchester County Medical Center, 1988), New York’s Appellate Court adopted a strict interpretation of the idea of substituted judgment. In this case, the court insisted that there is a duty to preserve life in all cases unless there is “clear and convincing evidence” that the patient intends to refuse treatment under a particular circumstance. The New York court was fearful that, without a strict standard of proof, the vulnerable older person could be abused by family members interested in inheriting property or by caregivers exhausted by the burden of care. Their concern was geronticide, or the killing of the old, a practice prevalent in some premodern societies facing conditions of extreme scarcity (Brogden, 2001).

In an attempt to guarantee that their wishes regarding life-sustaining treatment will be carried out, some people write living wills, but a living will does not answer all questions that can arise in end-of-life decisions. Consider the case of Estelle Browning of Florida (In re Guardianship of Estelle M. Browning, 1990), who suffered a massive stroke at age 86. In a previously written living will, Browning had stated that she wanted medical treatment, including artificial nutrition, withheld or withdrawn in the event that her condition was terminal and death was imminent. But did these provisions of her living will apply to the present condition? Browning was not in a coma, but damage from the stroke was extensive and irreversible. But is irreversible the same thing as terminal? The court eventually agreed to permit withdrawal of Browning’s feeding tube on the grounds of a right to privacy and in recognition of the substituted judgment rendered by a proxy decision maker.

One of the most important cases was that of Nancy Beth Cruzan (Cruzan v. Director of Missouri Department of Health, 1990), a young woman who suffered brain damage following an accident and was kept alive with artificial nutrition and hydration. A Missouri court denied her parents’ request to discontinue treatment, maintaining that clear and convincing evidence of Nancy’s wishes was not available. In 1990, this Missouri decision was upheld, by a 5–4 vote, by the U.S. Supreme Court. But by an 8–1 vote, the Supreme Court endorsed “the principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment.” At the same time, the court ruled that there were legitimate state interests in preserving life and preventing potential abuse in terminating treatment. For this reason, the court judged it proper to permit states to impose a high standard of evidence in determining whether an action by a surrogate decision maker (e.g., Cruzan’s parents) actually reflects the wishes of the patient.

The Cruzan case was the first time the U.S. Supreme Court had rendered a verdict on right-to-die cases. In its decision, it upheld the right to refuse life-sustaining care, including artificial nutrition as a medical treatment. A majority of the court found that an appointed proxy or surrogate decision maker, just like a competent patient, would be legally entitled to refuse treatment. Significantly, the court finally endorsed the use of advance directives (Doukas & Reichel, 2007) such as the living will and the durable power of attorney for health care. But the court also left procedural requirements to the states, ensuring that both legislation and litigation will continue for years to come.
In many ways, the recent evolution of right-to-die laws and court cases is a continuation of long-held cultural ideals: above all, the idea of self-determination and protection of rights by due process of law. For a competent adult, the right to refuse medical treatment, even at risk of death, has been widely recognized in U.S. common law tradition. The Natanson v. Kline case (1960) expressed the ideal of self-determination in these words: “Each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment.” But these developments do not confer on anyone a right to have active euthanasia performed, nor do they confer a right to involve other people in assisting with suicide. The right to die in all cases under law has involved some variety of passive euthanasia.

Should the right to die be extended further? Where to draw the line between a passive right to die and more active forms of assisted suicide or active euthanasia remains an unresolved issue. An early case, Perlmutter v. Florida Medical Center (1978), illustrates the point. A 73-year-old man was terminally ill, but deemed competent, and sought to have his respirator disconnected. The Florida state attorney argued that anyone helping to disconnect the respirator could be criminally charged with assisting a suicide, an argument that the Florida Supreme Court firmly rejected.

Today, few people would regard withdrawing treatment from the terminally ill as equivalent to suicide. Courts have repeatedly concluded that termination of life-sustaining treatment is not homicide, suicide, or assisted suicide. At the same time, assisting a suicide does remain a crime in most jurisdictions of the United States. This fact is important in weighing the actions of Dr. Jack Kevorkian, who in the 1990s developed a “suicide machine” that delivers a lethal dose of drugs to patients requesting it. The self-styled suicide manual, titled Final Exit (Humphry, 2002), remains popular among some older adults and those with terminal illnesses. Although a jury finally convicted Kevorkian, public opinion polls showed substantial support for him.

In 1997, in the Washington v. Glucksberg case, the Supreme Court ruled that terminally ill individuals do not have a constitutional right to assisted suicide. The result of this decision is that states may make their own regulations in this area, as Oregon did in the same year, becoming the first state to permit physician-assisted suicide; Washington, Montana, and Vermont later followed suit. In the first years after the law was passed, few people took advantage of the Death with Dignity Act (1997), which permits doctors to prescribe lethal medications for patients with a terminal illness who want to end their lives. The average age of those making use of the law to date has been 71, so the Oregon experience does have implications for an aging population (Sullivan, Hedberg, & Fleming, 2000). One interesting outcome of the new law has been vastly greater interest in Oregon in the use of pain medications, as well as hospice. The Oregon assisted-suicide law remains controversial.

Whatever the outcome of public debate over assisted suicide, many older people are taking matters into their own hands. According to the American Association of Suicidology, older adults have a higher suicide completion rate, though they attempt suicide less often, than any other age group. Although the suicide rate for women peaks in midlife, older men are more likely to commit suicide than any other group in the United States, most often using guns. But old-age suicide is a complex phenomenon (Leenaars et al., 1992). For instance, there are dramatic differences in suicide rates in later life among different ethnic groups. White men are the group most likely to kill themselves in old age, and Black women are the least likely to die by their own hands (Baker, 1994).
Despite wide public discussion, Americans, like citizens in other countries engaged in this important discussion, seem to lack a clear consensus about exactly how “the right to die” might be defined (Hendry et al., 2013). At a minimum, dying well would mean having the right to know one’s medical condition and the choice to accept or reject life-prolonging treatment. At the same time, there is growing public approval for the right of the terminally ill to have the options of euthanasia or assisted suicide. Some surveys suggest that two thirds of Americans favor legalizing physician-assisted suicide. One factor pushing public opinion in this direction is the loss of control that terminally ill patients experience in hospitals: Even completing an advance directive does not guarantee that it will be honored in practice.

What is distinctive about the current debate is that some critics are coming to view suicide in old age not as a problem, but perhaps as a rational choice in a desperate situation. The organization Compassion & Choices argues that suicide and assisted suicide in the face of a terminal illness that causes unbearable suffering should be ethically and legally acceptable. The Netherlands has gone furthest in legalizing euthanasia and physician-assisted suicide, and advocates of assisted suicide look favorably on the Dutch case (Pierson, 1998). But some observers see the experience of the Netherlands as proof of how difficult it is to effectively regulate euthanasia and suicide (Gomez, 1991). For instance, one study of the practice showed that for more than half the patients in the Netherlands who had legal euthanasia, the procedure was performed without their full consent (Butler, 1996). Critics have argued that, instead, the real focus should be on palliative care, such as hospice and better pain medication (Meier, 2011). Some opinion polls showing that a majority of Americans favor legalizing assisted suicide give different results if respondents are given a choice of better palliative care at the end of life (Shelanski, 1998).

GLOBAL PERSPECTIVE

Assisted Dying in Europe

Bettina Schardt, age 79, was a retired X-ray technician living in Würzburg, Bavaria, in Germany. She was old, but she was neither sick nor dying. Still, she wanted help in committing suicide. The reason? She did not want to move into a nursing home. In response to her request, an advocate of assisted suicide helped her to end her life and thus set off a furor of public debate in Germany. It turns out that many Germans do not want their country to follow the example of Switzerland, where liberalized laws on euthanasia have brought about a booming trade in assisted suicide. In recent years, almost 500 Germans have crossed the border into Switzerland in order to end their lives, a striking example of “medical tourism,” where people flock to foreign countries for medical services. Medical tourism is usually driven by lower prices, but in the case of assisted suicide, the motive is different. Advocates of assisted suicide believe that people are seeking a dignified way to end their lives. Critics point to Bettina Schardt as a case where unreasonable fears about nursing homes led to an irrevocable decision.

European countries present different options when it comes to assisted suicide and euthanasia. Assisted dying is legal in Belgium and the Netherlands, and it is tolerated and openly practiced in Switzerland. In Great Britain, laws have been proposed to liberalize assisted dying in the case of
By the time Karen Ann Quinlan died in 1985, public opinion in the United States had undergone a substantial change that paralleled dramatic developments in the legal sphere. Public opinion has continued to evolve in favor of greater choice about end-of-life decisions (Yankelovich & Vance, 2001). Recent polls by Harris and Gallup reveal that a majority of people believe that adults diagnosed with terminal illnesses have a right to a peaceful death through medical means. As well, withdrawal or withholding of heroic measures such as artificial respiration and cardiopulmonary resuscitation has become more acceptable to a majority of Americans, at least in cases of terminal illness. But most health care professionals and vocal elements of the public still disapprove of active euthanasia.

The issues remain controversial. In 2003, there was enormous publicity around the case of Terri Schiavo, a Florida woman who had for years been in a persistent vegetative state and kept alive by a feeding tube. Family members disagreed about whether to remove life support, and the Schiavo case was the subject of extended litigation and vast national publicity. Public opinion was polarized. Schiavo was eventually removed from life support and died in 2005.

The Schiavo case revealed that some issues around the right to die provoke vigorous dispute. For example, is artificial nutrition or hydration to be considered in the same category as other medical treatments? The AMA has claimed that there is no ethically significant difference between withdrawing food and water and using other life-supporting measures. Most medical ethicists and courts have agreed. But many laypeople and professionals remain unconvinced.

In a similar way, ethicists have argued that withholding life-supporting treatment is no different morally from withdrawing treatment once it has already begun. But again, most families and health care practitioners remain persuaded that there is an important psychological difference: It is easier not to start a treatment than it is to withdraw it once begun. Clearly, the social and interpersonal context of a decision continues to make a difference to those involved in end-of-life decisions.

A major step in the process of resolving these issues came with the enactment of the Patient Self-Determination Act (PSDA), which went into effect in 1991. This law requires hospitals, nursing homes, and other health care facilities to advise all patients at the point of admission about their right to accept or refuse medical treatment. The PSDA in effect creates new requirements for hospitals, but it does not create new rights for patients. Under the law, patients are specifically to be told about their right to determine in advance whether they wish to have life-sustaining treatment if they become ill without hope of recovery. The staff members of health facilities are required to document and implement policies that respect the wishes of patients (LaPuma, Orentlicher, & Moss, 1991).

Despite this law, however, relatively few patients actually complete an advance directive of any kind. Public opinion polls have revealed that close to 90% of American adults would not want to be maintained on life support systems without prospect of recovery. Yet a survey by the AMA revealed that not even 15% of the general public had actually completed a living will, and a low proportion holds true for persons ages 65 and older.

Why is the proportion so low? It appears that physicians in general favor the idea of advance directives, but they remain reluctant to engage in an open discussion with patients on the topic. Recent research confirms the assumption that many Americans today prefer to be told the truth about their medical diagnoses. Yet substantial proportions of Asian American and Hispanic elders are less likely than others to favor an autonomy model of decision making, and practitioners need to take into account these ethnic differences in communicating with older people (Braun, Pietsch, & Blanchette, 2000). The PSDA is unlikely to be the final answer to helping patients make end-of-life decisions. In 1997, the U.S. Supreme Court (in Vaco, Attorney General of New York, v. Quill) issued a landmark decision that assisted suicide is not a constitutional right, thus leaving the matter up to individual state legislatures. Neither court decisions nor legislative action will put an end to the ethical debate about right-to-die issues, which is certain to continue for many years to come. Physician-assisted suicide has been permitted for some time in several European countries (Belgium, Luxembourg, the Netherlands, and Switzerland). For many years, Oregon was the only U.S. state in which physician-assisted suicide was legally permitted, but Oregon has now been joined by Washington, Vermont, and California. In contrast to advance directives, assisted suicide and euthanasia remain topics of intense debate (Pappas, 2012). Advocates believe in personal autonomy—"death with dignity"—while opponents worry about a "slippery slope" that could put the disabled and older people at risk.

In the readings that follow, we hear impassioned voices in the debate over the right to die. Robert A. Pearlman and Helene Starks offer some powerful case histories along with data from surveys that help answer the question of why some people seek physician-assisted death. The answer, it turns out, has less to do with physical pain and more to do with threats to our sense of personal integrity. Charles F. McKhann speaks in favor of physician-assisted suicide under certain circumstances. A mixed message comes from Sue Woodman in her article, “Last Rights: Aunty’s Story.” She explores how the same person’s feelings toward suicide and euthanasia can change over time. Woodman’s article shows how complicated these decisions can be in practice.

In contrast, Leon Kass decisively rejects the idea of assisted suicide. Kass offers strong arguments for why doctors must never kill and why physician-assisted suicide is morally wrong. Kass’s arguments force us to think carefully about a basic question arising in end-of-life decisions. To what extent is the decision to end one’s life a purely individual matter, and to what extent does it involve other people? For example, does the ending of one’s life become a different matter because physicians, family members, or others participate or assist in the act of suicide? As individuals and society debate the issue in years to come, we will be preoccupied with the question of how individual choices are connected to wider values, such as the cost of health care and the condition of old age in our society.
FOCUS ON PRACTICE

Advance Directives

The ethical dilemmas of end-of-life decisions have increasingly led to demands for a greater measure of control in how those decisions are made. One practical response has been the spread of so-called advance directives, or written statements prepared well before a serious illness arrives, in which an individual can state the choice to be made when a decision is necessary (Lack, Biller-Andorno, & Brauer, 2014).

Under the law, everyone already has the right to refuse all or any part of medical treatment if it isn’t desired. But sometimes, because of diminished medical capacity, people are unable to let others know whether they would want a specific treatment. An advance directive solves this problem by giving specific directions or designating someone else in cases an individual is unable to express a wish about medical treatment.

There are two general types of advance directive: Both are intended to give guidance and retain validity even after the person who executed the document has lost mental capacity. As mentioned, these are the living will and the durable power of attorney for health care. A living will is a written statement expressing an individual’s wish for what should be done in a life-threatening situation. It permits physicians to stop undesired medical treatment even if stopping treatment might result in death. If a clear living will has been drafted beforehand, everyone can know that the patient would want life-sustaining treatment withdrawn.

A second legal instrument naming a specific person to make health care decisions is the durable power of attorney for health care. This instrument permits a person to designate, in advance, another person who is trusted to make health care decisions for the patient in the event that he or she becomes incapacitated.

A living will permits an adult of sound mind to stipulate the kind of life-prolonging treatment to be provided in the event of an emergency when the patient cannot indicate a choice—for example, “I desire food and fluids but no cardiopulmonary resuscitation.” It is a legal document and should be prepared on a standard form, although a simple written declaration of preference may also suffice. Different states have different legal requirements about witnesses and other rules for writing a living will.

A durable power of attorney is also a witnessed legal document. But an individual need not specify all the details about treatment to be given or withheld. Instead, the individual designates someone else—called a proxy or a health care agent—to make those decisions in the event the patient is incapacitated. This proxy could be a family member, a close friend, or any trusted person. As with living wills, different states have varying rules and regulations applying to power of attorney documents and their acceptability for health care decision making.

Federal law now requires hospitals, nursing homes, and other health providers covered by either Medicare or Medicaid to give people information about advance directives. No one is required to fill out an advance directive, but organizations are required by law to let patients know that they have the right to do so.

(Continued)
If you have an advance directive, this legal tool goes into effect only if you are unable to speak on your own behalf. An advance directive doesn't prevent you from changing your mind at a later date if you are conscious and able to act on your own behalf. An advance directive can be changed or canceled by the person who wrote it at any time.

People sometimes ask whether a living will or a durable power of attorney is better. Living wills were the first type of advance directive to become popular, but health care powers of attorney have turned out to be more flexible. The exact kind of document required depends on state laws, which have become a critical factor in light of the *Cruzan* decision. Such variations in law from state to state can, of course, be a problem because it is unclear whether one state will always honor a directive from another state.

When end-of-life decisions must be made in the absence of a written directive, the decision about discontinuing treatment is typically made by the family and health care providers in consultation. It is rare for such decisions to end up being made by a court, which is a cumbersome way to proceed. Written advance directives can be helpful in keeping such cases out of the legal system and in the hands of those closest to patients.

At this point, although awareness of the importance of preparing an advance directive has increased, only a small proportion of Americans—fewer than one in three—have actually prepared any kind of written advance directive. Why don't more older people use advance directives?

Studies of interventions to promote advance directives have shown people are much more likely to complete these documents if they're given help by families or health professionals.

Advance directives in any case may not be the total solution for end-of-life decisions. For example, in a study of patients on kidney dialysis, 61% said they wanted the doctor or proxy decision maker to have “leeway” to disregard the patient’s own previously expressed preferences. Instead of simply following a living will, decision makers were supposed to take into account circumstances and the patient’s best interest.

Some critics have argued that the move toward advance directives may end up making decisions to refuse treatment easier only for those who have filled out the necessary “paperwork.” Those who have not completed the proper legal documents—for instance, persons without the necessary information or education—may find themselves lacking rights theoretically granted to them by law.

Still other critics argue against advance directives because people often change their minds about end-of-life decisions. It is common for older people to say, “I would never want to live in an old-age home.” Yet after living for a time in a retirement residence or nursing home, the same people often discover that life is quite satisfactory there. That same point could hold true for living with chronic illness. People fear they would be unable to go on living under an extreme disability, yet adaptation to loss and living with disability does take place.

Recent critics have gone so far as to speak of the “failure” of the whole idea of living wills, favoring instead a stronger use of the durable power of attorney, which, of course, has its own problems (Fagerlin & Schneider, 2004). These problems, however, do not make advance directives a bad idea. Instead, they suggest a need to improve the way advance directives are used in practice. For example, we should strengthen communication between health care professionals and patients and not simply treat written directives as another form of paperwork. The need for better...
communication also suggests that advance directives can be an occasion for family members to share with one another their own values and expectations. Used in this way, advance directives can help older people and their families better approach end-of-life decisions. The more recent innovation of Physician Orders for Life-Sustaining Treatment (POLST) proves that the approach of advance directives can be made more practical and effective (Fromme et al., 2012).

URBAN LEGENDS OF AGING

“Advance directives would have prevented the tragic case of Terri Schiavo.”

Not at all. Her husband Michael would almost surely have been appointed proxy decision maker, since the spouse is already presumed to be as such by the courts and common law. As for living wills, they have been shown by empirical studies to be mostly underutilized and therefore ineffective. In any case, Terri Schiavo was not terminally ill, and an advance directive almost certainly would not have prevented her tragic case.
Despite the illegality of physician-assisted death in the United States (except in the state of Oregon), many primary care providers and oncologists have been asked to provide aid in dying. Popular explanations for physician-assisted death include inadequate treatment for pain or other symptoms, depression, hopelessness, and socioeconomic stressors, such as concerns about the burden of increasing dependency on other members of the family and the economic hardship associated with the costs of health care.

What motivates people to pursue physician-assisted death has proved to be both a controversial and a foundational issue in debates regarding the legality of and appropriate clinical response to requests for aid in dying. To date, insights regarding the motivations for assisted death have come largely from three sources: provider impressions, patients who transiently consider physician-assisted death or other means to end their lives under certain conditions, and forced-choice reporting (that is, responding to a checklist of reasons) from patients in Oregon who have pursued physician-assisted death. However, there has been limited direct reporting from patients about the motivation and process that lead them to pursue assisted death.

To address the current gaps in the understanding of physician-assisted death, we conducted a longitudinal, qualitative study of patients who seriously pursued assisted death and their family members. The patients in our study lived an average of ten months between their first request for aid in dying and the time of death. Patients used this time to acquire the means to end their lives. For many, however, simply having medications did not result in their immediate use. These patients engaged in an ongoing evaluation of the value of living versus dying and repeatedly assessed the benefits and burdens of their current experience. Moreover, among the individuals in our study, the pursuit of physician-assisted death was not motivated by any single factor, nor was depression reported as a reason. Rather, the decision to hasten death culminated from an interaction of illness-related experiences, threats to the person’s sense of self, and fears about the future.

The reports from these patients and their family members identified opportunities for improving palliative care that might have reduced patients’ perceived need to choose aid in dying. However, these accounts also illustrate why a small number of patients will continue to view assisted death as a desirable choice. Some will decide that hospice and palliative care are not for them or that some of the choices offered by palliative care, such as the trade-off between pain management and cognitive function, are not acceptable ones. In addition, some issues, such as the desire to control the dying process and the suffering associated with a loss of sense of self, are not easily addressed even by the most capable health care providers.

After exhausting her anticancer treatment options, Anna became very weak, sleeping much of the day, and was unable to perform many of her routine functions. She started bleeding uncontrollably from her bowel as a late side effect of total abdominal radiation and was told that the only treatment was constant transfusions. She told her husband, “Honey, this is it: I can’t do this anymore.” Over the next thirty-six hours, Anna gathered her family together to say goodbye. She ingested the medication to hasten her death, with twelve loved ones in attendance, and died within two hours.

**Factors Motivating Physician-Assisted Death**

In our interviews with thirty-five families, we asked questions about the history of the patient’s illness, the patient’s stated reasons for seeking aid in dying, and other factors influencing the pursuit of physician-assisted death, as well as the manner of death. Our analysis identified nine common factors. No single factor on its own ever accounted for a serious interest in a hastened death. Rather, interest usually arose out of an interactive process involving multiple factors in three broad categories: illness-related experiences (symptoms, functional losses, effects of pain medication, and the like), threats to the person’s sense of self (as revealed by his or her desire for control over the circumstances of dying and long-standing beliefs in favor of hastened death), and fears about the future. Figure 1 presents our assessment of the frequency and importance of these factors in the patients’ deliberations.

**Illness-Related Experiences**

Weakness, tiredness, and discomfort made up one set of motivating concerns for patients who sought aid in dying. Excellent end-of-life care can often ameliorate these concerns. However, the functional losses caused by advanced illness...
Basic Concepts II  Aging, Health Care, and Society

are often less amenable to successful intervention, especially when the patient is dying. Approximately two-thirds of the patients in our study described the relation between symptoms brought on by illness and treatment and the resultant loss of function as considerations in their pursuit of assisted death. For example, a woman with ovarian cancer spoke of the effects of chemotherapy: “Of course, with me, with the chemo and things, [there’s] just the terrible weakness and the nausea and just not feeling like you can do anything . . . . If it’d been like two weeks after and I was going out to do things—but you were still shaky, and you couldn’t quite predict how you were going to feel, or you were afraid to make commitments because you weren’t sure you were going to be able to carry them out.” Physical symptoms often led to a lack of function. For example, one woman described her response to steroids for her chronic lung disease:

My thighs are so weak I can’t get up from the floor, and I don’t have energy. . . . My arms are withering away. It’s ridiculous. And also I take stuff with [prednisone] that gives me stomach problems, and I have bowel problems—there is no part of me that is functioning routinely. I’m very, very tired, and I cough a lot. My cough is worse when I talk a lot, and early in the morning it’s horrible. I cough all this yucky stuff up and can’t talk a lot. And I’m so weak, for example, that although I can drive a car, I find it just too much to lift my own oxygen tank up and in and out of the car. . . . So I’m not living; I’m existing.

Pain and the side effects of treatment for pain were another set of motivating issues for more than a third of the patients in our study. As others have argued, pain can be better managed with excellent end-of-life care.5 However, the side effects of treatment, especially effects on cognition, will continue to be challenging. For some patients, these side effects are totally unacceptable, and feeling that they must choose between being pain free and being mentally competent creates the desire for another alternative—a hastened death. One woman described her mother’s situation as follows:

She was in a lot of pain. . . . What she feared more than the pain was the effect that the pain drugs would have on her. . . . She didn’t want to lose her rational mind. She didn’t want to lose any of her personality or capacity. . . . Certainly, [she had a] fear of the pain increasing and causing her to have to take more medication . . . . enough that she didn’t really know what she was doing all the time or that she might start drooling or saying stupid things or coming across as drunk.

In another case, a man had metastases to his spine causing severe pain that was difficult to control, despite large doses of morphine. Hospice nurses had attempted to control his pain but ended up sedating him completely for twenty-four hours, which he found absolutely unacceptable. His wife told us,

Pain was an extraordinary factor. He would go out and split kindling . . . . and I kept saying, “I’m going to have more kindling than Carter has pills.” And he says, “It gives me something to do, and if I have something to do, I don’t have to think about how badly it hurts.” Pain was an extreme factor . . . . and he was not a sissy, not at all. . . . [But] the morphine pump didn’t do it. He was still taking Roxicet . . . . This had been going on for months, and so by that time his body had built up a tremendous tolerance. . . . They could knock him out; he could be a vegetable; but that was not what he wanted. . . . If he couldn’t function and at least think somewhat clearly, life wasn’t worth it. And he did not want to leave me. He did everything possible to set me up, because he knew he was going to die. . . . There was no way you could stop that. And he did everything imaginable to make my life as easy as it could be. But it got to a point where the pain was just intolerable.
**Threats to Sense of Self**

The literature suggests, indirectly, that depression and hopelessness may motivate some patients to seek a hastened death. However, acute depression was not judged to be an influential factor for any of our participants. The more common motivating issues of a psychological nature pertained to loss of control and sense of self (both experienced by nearly two-thirds of our patients). Most experts in end-of-life care acknowledge that redirecting the loss of sense of self in a dying patient is a daunting challenge and one that is rarely achieved. This form of suffering is profound and is related to losses in relational, social, and community involvement.

These losses affect not only what one can do but how one perceives oneself. One woman described her mother’s response to progressive losses owing to an autoimmune disorder:

> My mother was at age seventy-two before she got sick. She was still very energetic and vibrant, youthful and active and looked ten years younger than she was. And then when she got sick, she started losing her hair, and she became disfigured with this skin condition. She would, literally, have spells when her muscles would be so bad that she would feel paralyzed, and she was in incredible fear of becoming paralyzed and becoming completely incapacitated and immobile. [She wanted to have] control over her own dignity and her own independent life. The things that were meaningful to her in her life were her art, her ability to do her art, and her friends and spending time with her friends and cooking and eating. She was ... convinced that when she couldn’t do any of those things anymore, her life would be meaningless, and she wouldn’t want to live anymore.

In another example, a man described his mother’s final sense of loss when she could no longer visit with her extensive network of family and friends:

> She lost her appetite, her pleasure for food. She lost her strength to go outside and even having ... people come over. She’d try. She hated to say no, they couldn’t visit. She wanted to, but a visit was a painful process. She just didn’t have the strength or the concentration ... to even visit with people anymore. So basically, even having company is a strain, a pain to you, almost more than it’s a pleasure to enjoy the people. And that was about the last thing she had left, was just sitting around and enjoying people, and even that went away. Like she said, you get so sick of being sick and tired.

For most patients, sense of self is inextricably connected to ability to function. Moreover, the loss of sense of self creates appreciable anxiety. For example, one woman had metastases to the bone and was at risk for a spinal compression that would lead to paraplegia and incontinence. This functional loss represented more to her than just another accommodation to her illness. Her daughter explained the patient’s view about her future:

> She saw this declining physical curve, and that at some point along that she was going to lose significant ability to be the person that she was. And she had already lost a lot—she couldn’t go for the long hike anymore, ... she couldn’t go for the long walks, and now she wasn’t supposed to work full time, and she was completely exhausted all the time, because she was working and taking care of her big house and all. So she had already seen some things go, and that was acceptable, but she knew at some point she’d be somewhere down on the curve [where] she had given up so many things that it wasn’t okay. Rather than wait to get there and have to figure out where that point was, she wanted to just die before it got any worse. And then when her spine started to go, of course, the big threat was losing control of her bowels, [which] was clearly not acceptable.
Fears About the Future

Fears about the future, including fears about the experience of dying, also motivate patients who seek to hasten death. Many of the patients projected that the course of their illness would result in a fate worse than death and preferred to end their lives before they reached this condition. Their judgments about this poor quality of life were often based on their own prognosis, accumulated losses, and fears of becoming a burden on others. For about half of our patients, their fears were also influenced by having witnessed loved ones go through terrible deaths involving pain, what they viewed as pointless use of medical technologies, and images of tubes coming out of every orifice. With better palliative and end-of-life care, fears like these should abate as people see others having better dying experiences. Nonetheless, even the best palliative care cannot prevent all functional losses and loss of sense of self, and thus for some, these fears will remain and motivate them to seek aid in dying.

Implications for End-of-Life Care

Several important implications for clinicians emerge from these case reports. First, that multiple interacting factors prompt patients to seek

Figure 1  Motivations for Seeking a Hastened Death

<table>
<thead>
<tr>
<th>Motivating Factor</th>
<th>Total Patients^a (N = 35)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Illness-related experiences</strong></td>
<td></td>
</tr>
<tr>
<td>Feeling weak, tired, and uncomfortable</td>
<td>24 (69%)</td>
</tr>
<tr>
<td>Loss of function</td>
<td>23 (66%)</td>
</tr>
<tr>
<td>Pain or unacceptable side effects of pain medication</td>
<td>14 (40%)</td>
</tr>
<tr>
<td><strong>Threats to sense of self</strong></td>
<td></td>
</tr>
<tr>
<td>Loss of sense of self</td>
<td>22 (63%)</td>
</tr>
<tr>
<td>Desire for control</td>
<td>21 (60%)</td>
</tr>
<tr>
<td>Long-standing beliefs in favor of hastened death</td>
<td>5 (14%)</td>
</tr>
<tr>
<td><strong>Fears about the future</strong></td>
<td></td>
</tr>
<tr>
<td>Fears about future quality of life and dying</td>
<td>21 (60%)</td>
</tr>
<tr>
<td>Negative past experiences with dying</td>
<td>17 (49%)</td>
</tr>
<tr>
<td>Fear of being a burden on others</td>
<td>3 (9%)</td>
</tr>
</tbody>
</table>


NOTE: Motivating factors were rated independently by two investigators as to their role in influencing the pursuit of a hastened death. Four response categories were recorded: “not mentioned,” “present but not judged to be influential,” “influential,” and “very influential.” The table records response ratings inferred to be “influential” or “very influential” based on the reading of the transcripts.

^ Total patients included prospective and retrospective cases. Prospective cases included patients and family members recruited while the patient was alive. Retrospective cases included only surviving family members recruited after the patient’s death.
assisted death challenges health care providers, including those in palliative care, to understand patients’ illness and dying experiences holistically. Our patients reported intricate and subtle interactions between physical and functional decline and existential concerns that could not be easily separated or compartmentalized. Our data confirm the familiar recommendation that providers repeatedly assess the patient’s concerns about losses and dying in order to understand patients’ concerns and tailor end-of-life care of the patient’s evolving personal experience.

Second, these narrative accounts also demonstrate the importance to patients of their sense of self and of control over the manner of death. Clinicians need to be sensitive to these deeply personal psychological and existential issues and differentiate them from clinical depression. Although it is important to determine whether depression is driving a request for assisted death, it is equally important to examine other psychological processes.

Finally, the factors that motivate an interest in assisted death are similar to those that prompt people to complete advance directives and forgo life-sustaining treatment: the desire to control the timing and circumstance of one’s death. Many people view assisted death as another option that should be available at the end of life. The topics identified in Figure 1 can serve as a guide in talking to patients about the far-reaching effects of illness, including the quality of the dying experience. Clinicians should explore patients’ fears and how they see themselves in light of current and future physical decline and functional losses. Clinicians frequently shut down discussion about aid in dying and, in so doing, thwart opportunities for understanding patients’ responses to their dying experience. Instead, clinicians must explore the motivations for these patients’ interest in this option and identify ways to ameliorate their suffering. For some patients, however, the amelioration of suffering will come only with death, and these patients may be unwilling to endure a prolonged dying process.

Our study suggests that some dying patients will continue to desire a hastened death in spite of excellent palliative end-of-life care. Some suffering cannot be relieved and will continue or worsen. The question that must be asked is, Are we as a society sufficiently compassionate to allow the choice of a hastened death to terminally ill, competent patients who are receiving state-of-the-art end-of-life care but are still suffering?

**Notes**


My interest in physician-assisted dying and the earliest impetus to write this book grew out of my father’s death in one of the best hospitals in the country. A physician himself, he died in...
1988, at the age of eighty-nine, with widespread intra-abdominal cancer. In the process, he was kept alive for more than a month when his outlook was clearly hopeless. At one point he asked whether I thought he was on his deathbed. When I said that he probably was, he replied, “That’s what I think, too, and I wish they would just let me go.” He complained to us on several occasions that too much was being done, that he just wanted to be left alone. In truth, we don’t know what he said directly to his doctors, but we passed his concerns on to them, along with our own. We were assured that they were “doing everything possible” for our father. Everything possible included palliative surgery, blood transfusions, and intravenous feedings. Even his two physician sons, one of whom is on the staff of the same hospital, were unable, or too timid and conflicted, to influence the decision making so that he might be allowed to die sooner.

It seems unfair that people who manage their own affairs successfully in life should be required to turn over so much of their death and dying to others. We direct the disposition of our belongings through wills and trusts, but except for the limited protection provided by “living wills,” we have no such control over the conditions of our death, and the physicians who have this responsibility may be deaf to our entreaties and those of our families. Behind them stand tradition, a conservative profession, and the law. Regardless of a physician’s personal compassion, helping people to die is risky in today’s atmosphere. This atmosphere is changing, though, and one can already distinguish between the conservative views of medical societies—representing “the profession”—and those of practicing physicians who are concerned about the suffering of their patients. Many physicians have helped people to die, and many more would be willing to do so if it were legal.

Given a choice, most of us would like to live to old age, satisfied that we have accomplished what we could, and then to die peacefully, perhaps with enough warning to say our good-byes, but without undue suffering from prolonged illness. Old age, however, can be marred by severe disability, and death may not be kind or peaceful. Acute infections that killed swiftly and relatively painlessly fifty years ago have been replaced by organ failures and chronic diseases that take their victims slowly and sometimes very painfully. Through the passing of friends and relatives we have learned that there are good deaths and bad deaths, even horrible deaths. What term then is best applied to the person who wishes to die and asks for help? The death is intended and expected, both by the person dying and by the person providing the help. Both also anticipate that the death will be accomplished in a gentle and humane fashion, not a violent one. The assistance is a compassionate response to an individual’s considered wishes. The term that I will use is physician-assisted dying, rather than assisted suicide.

Dying is a much more appropriate term than suicide for people who are already terminally ill. More accurately, assisted dying includes both assisted suicide, in which the patient must bring about his own death with materials provided by a physician, and euthanasia, in which the physician directly causes the death. Morally, they are quite similar activities, and eventually I think that both should be made legal. But there are also important differences, and in the immediate future the public, the medical profession, and our legal processes will be looking only at assisted suicide. Any consideration of assisted dying, however, requires acceptance of the concept of rational suicide—namely, that there are circumstances when death is clearly preferable to continued suffering. The question of whether suicide is ever morally acceptable is really the heart of the controversy.

The current movement for assisted dying began in direct response to the requests of individual patients and has expanded to the level of public demand. Society’s concern about unnecessary suffering at the end of life is reflected in recent polls, which show that about 65% of people in the United States favor legislation that would permit physician-assisted dying.
Many feel that their own needs should be placed above those of their physicians or the medical profession. They feel that even the promise of help would increase their confidence in their physicians and would allow them to better enjoy their remaining days.

Public concerns about assisted dying include the roles of various financial interests in prolonging or shortening life, the possibility of medical error, the potential for abuse, and the chance of a misstep onto a “slippery slope” leading to irreversible moral decay of our society. Abuse could come at the hands of family, custodians, or even physicians. The slippery slope could be a devaluation of life by individual physicians, the medical profession, even society as a whole. As a result, euthanasia could be legally extended beyond the limits of voluntary subjects to incompetents, and then still further to a spectrum of disadvantaged people: the poor, racial minorities, and the handicapped. These important concerns, which have become the cornerstones of most of the opposition to assisted dying, must be analyzed, understood, and addressed.

The differing views on assisted dying must eventually be assimilated into constructive laws that meet the needs of those immediately affected while protecting all others.

Oregon was the first state to pass a law permitting physician-assisted dying. For such laws to succeed they must include appropriate safeguards, but not so many restrictions as to make them unworkable. Several models are evolving through legislative attempts in different states. Some will succeed.

A rational decision or action is one that is well thought out by a competent individual, for reasons that are understood and can be explained to others. To wish to die in order to be spared unendurable pain from illness is seen by many as perfectly rational.

Quality of life to the last and control over the circumstances of dying are issues that touch everyone, and assisted dying will become legal and accepted when the public wants it to be. It is essential that the issues be understood, recognizing that today’s needs are not necessarily met by yesterday’s laws, that reason can counteract dogma, and that hypothetical fears of tomorrow’s abuse and the slippery slope can be tested against today’s reality in our own society. Assisted dying is destined gradually to be accepted as an end-of-life option. The trend will begin with assisted suicide in a few states, then spread to other states as voters and legislators see that it is desirable and socially safe. After it becomes acceptable in many states, the courts may step back in to provide similar protection for people residing in more conservative parts of the country. Eventually, assisted dying should be extended to include euthanasia for some people, and the range of underlying disorders should be extended to include neurological diseases that entail severe suffering but are not necessarily fatal, dementia, and even severe debility from old age. Assisted dying must be an option that can be requested by those who have lived with dignity and are determined to die the same way.
INTRODUCTION

I received a call summoning me back to London, where I grew up, to the hospital bedside of my 90-year-old aunt. Aunty, as she is known to family and friends alike, had fractured her leg during a fall, and the physicians decided they would have to operate to reset the bone. When I arrived at the hospital the following morning, the physician told me that Aunty had survived the operation itself, but there was a problem. Perhaps related to her fracture, perhaps not, she had developed a blood clot in the broken leg, and no blood was reaching her toes or lower calf. The leg would have to be amputated some way above the knee. If not, he said, Aunty would die of gangrene, probably within a week.

And now, at age 90, she had come on another horror. At one point, she wondered aloud what evil she had ever done to deserve such a cruel fate.

I asked her whether she was afraid to die. “No, no, I’m not afraid,” she answered emphatically. “I would love it—just to go to sleep, to be finished. . . .” I tried to explain that this would be more or less possible: She could refuse the amputation, and allow her poor, battered, worn-out old body to die. The nursing staff promised they would make the process as easy and painless as possible; the morphine was already on order. Out of my love for her, I secretly prayed that she would choose this course of action.

It took Aunty a year and a half to die after her amputation. It was a heartbreaking time during which she lost not only her physical independence and the ability to do the things she loved—traveling, going to parks, and cooking meals for her family—but ultimately also her will to live.

From the time she was admitted to hospital after her fall, she was never able to return to her home again; she was moved from the hospital to a long-term rehabilitation unit, and after 7 months there, to an old-age home. Although she worked hard at the rehab hospital to learn to use a prosthetic leg, she didn’t have enough upper-body strength to manage it. Confined to a wheelchair, she could no longer look after herself and felt demeaned and appalled every time she had to summon a nurse to take her to the bathroom.

So Aunty would sit gazing out of her window for days on end, her mood alternating between blunt depression and a frantic, lashing rage about how wretched her life had become. By Christmastime, she was telling everyone who would listen that she wanted to die. She begged her nurses and her physician to help her. Of course, they said they couldn’t.

She told me that had she known what her life would be like after the amputation, she would never have gone ahead with it. But I wonder: When she was faced with that decision, she was not ready to die; she couldn’t.

imagine how diminished her life would become—what it would mean when stripped of all of the activities she prized. How difficult it must be for anyone to choose death when, up until that point, they have only experienced life under normal circumstances. After all, the survival instinct is powerful indeed: I saw for myself how tenaciously Aunty clung to hope, even at age 90; the hope of walking again, and when that failed, the hope that she could use an electric wheelchair to gain some kind of freedom. She didn’t give up hope for a very long time.

When she did, she was ready: ready to die, prepared and unafraid. And by being with her during those last days, I saw how sometimes, dying is not tragic and terrible, but simply an inevitable end, a relief and a release. I had never experienced a death like that before: a quiet, natural culmination of a long life fully lived.

READING 33

Neither for Love nor Money

Why Doctors Must Not Kill

Leon Kass

Contemporary Ethical Approaches

The question about physicians killing is a special case of—but not thereby identical to—this general question: May or ought one kill people who ask to be killed? Among those who answer this general question in the affirmative, two reasons are usually given. Because these reasons also reflect the two leading approaches to medical ethics today, they are especially worth noting. First is the reason of freedom or autonomy. Each person has a right to control his or her body and his or her life, including the end of it; some go so far as to assert a right to die, a strange claim in a liberal society, founded on the need to secure and defend the unalienable right to life. But strange or not, for patients with waning powers too weak to oppose potent life-prolonging technologies wielded by aggressive physicians, the claim based on choice, autonomy, and self-determination is certainly understandable. On this view, physicians (or others) are bound to acquiesce in demands not only for termination of treatment but also for intentional killing through poison, because the right to choose—freedom—must be respected, even more than life itself, and even when the physician would never recommend or concur in the choices made. When persons exercise their right to choose against their continuance as embodied beings, doctors must not only cease their ministrations to the body; as keepers of the vials of life and death, they are also morally bound actively to dispatch the embodied person, out of deference to the autonomous personal choice that is, in this view, most emphatically the patient to be served.

The second reason for killing the patient who asks for death has little to do with choice. Instead, death is to be directly and swiftly

given because the patient's life is deemed no longer worth living, according to some substantive or "objective" measure. Unusually great pain or a terminal condition or an irreversible coma or advanced senility or extreme degradation is the disqualifying quality of life that pleads—choice or no choice—for merciful termination. Choice may enter indirectly to confirm the judgment: If the patient does not speak up, the doctor (or the relatives or some other proxy) may be asked to affirm that he would not himself choose—or that his patient, were he able to choose, would not choose—to remain alive with one or more of these stigmata. It is not his autonomy but rather the miserable and pitiable condition of his body or mind that justifies doing the patient in. Absent such substantial degradations, requests for assisted death would not be honored. Here the body itself offends and must be plucked out, from compassion or mercy, to be sure. Not the autonomous will of the patient, but the doctor's benevolent and compassionate love for suffering humanity justifies the humane act of mercy killing.

As I have indicated, these two reasons advanced to justify the killing of patients correspond to the two approaches to medical ethics most prominent in the literature today: the school of autonomy and the school of general benevolence and compassion (or love). Despite their differences, they are united in their opposition to the belief that medicine is intrinsically a moral profession, with its own immanent principles and standards of conduct that set limits on what physicians may properly do. Each seeks to remedy the ethical defect of a profession seen to be in itself amoral, technically competent but morally neutral.

For the first ethical school, morally neutral technique is morally used only when it is used according to the wishes of the patient as client or consumer. The implicit (and sometimes explicit) model of the doctor-patient relationship is one of contract: The physician—a highly competent hired syringe, as it were—sells his services on demand, restrained only by the law (though he is free to refuse his services if the patient is unwilling or unable to meet his fee). Here's the deal: for the patient, autonomy and service; for the doctor, money, graced by the pleasure of giving the patient what he wants. If a patient wants to fix her nose or change his gender, determine the sex of unborn children, or take euphoriant drugs just for kicks, the physician can and will go to work—provided that the price is right and that the contract is explicit about what happens if the customer isn't satisfied.¹

For the second ethical school, morally neutral technique is morally used only when it is used under the guidance of general benevolence or loving charity. Not the will of the patient, but the humane and compassionate motive of the physician—not as physician but as human being—makes the doctor's actions ethical. Here, too, there can be strange requests and stranger deeds, but if they are done from love, nothing can be wrong—again, providing the law is silent. All acts—including killing the patient—done lovingly are licit, even praiseworthy. Good and humane intentions can sanctify any deed.

In my opinion, each of these approaches should be rejected as a basis for medical ethics. For one thing, neither can make sense of some specific duties and restraints long thought absolutely inviolate under the traditional medical ethic—e.g., the proscription against having sex with patients. Must we now say that sex with patients is permissible if the patient wants it and the price is right, or, alternatively, if the doctor is gentle and loving and has a good bedside manner? Or do we glimpse in this absolute prohibition a deeper understanding of the medical vocation, which the prohibition both embodies and protects? Indeed, as I will now try to show, using the taboo against doctors killing patients, the medical profession has its own intrinsic ethic, which a physician true to his calling will not violate, either for love or for money. . . .
Assessing the Consequences

Although the bulk of my argument will turn on my understanding of the special meaning of professing the art of healing, I begin with a more familiar mode of ethical analysis: assessing needs and benefits versus dangers and harms. To do this properly is a massive task. Here, I can do little more than raise a few of the relevant considerations. Still the best discussion of this topic is a now-classic essay by Yale Kamisar, written thirty years ago. Kamisar makes vivid the difficulties in assuring that the choice for death will be freely made and adequately informed, the problems of physician error and abuse, the troubles for human relationships within families and between doctors and patients, the difficulty of preserving the boundary between voluntary and involuntary euthanasia, and the risks to the whole social order from weakening the absolute prohibition against taking innocent life. These considerations are, in my view, alone sufficient to rebut any attempt to weaken the taboo against medical killing; their relative importance for determining public policy far exceeds their relative importance in this essay. But here they serve also to point us to more profound reasons why doctors must not kill.

There is no question that fortune deals many people a very bad hand, not least at the end of life. All of us, I am sure, know or have known individuals whose last weeks, months, or even years were racked with pain and discomfort, degraded by dependency or loss of self-control, isolation or insensibility, or who lived in such reduced humanity that it cast a deep shadow over their entire lives, especially as remembered by the survivors. All who love them would wish to spare them such an end, and there is no doubt that an earlier death could do it. Against such a clear benefit, attested to by many a poignant and heartrending true story, it is difficult to argue, especially when the arguments are necessarily general and seemingly abstract. Still, in the aggregate, the adverse consequences—including real suffering—of being governed solely by mercy and compassion may far outweigh the aggregate benefits of relieving agonal or terminal distress.

The “Need” for Mercy Killing

The first difficulty emerges when we try to gauge the so-called “need” or demand for medically assisted killing. This question, to be sure, is in part empirical. But evidence can be gathered only if the relevant categories of “euthanizable” people are clearly defined. Such definition is notoriously hard to accomplish—and it is not always honestly attempted. On careful inspection, we discover that if the category is precisely defined, the need for mercy killing seems greatly exaggerated, and if the category is loosely defined, the poisoners will be working overtime.

The category always mentioned first to justify mercy killing is the group of persons suffering from incurable and fatal illnesses, with intractable pain and with little time left to live but still fully aware, who freely request a release from their distress—e.g., people rapidly dying from disseminated cancer with bony metastases, unresponsive to chemotherapy. But as experts in pain control tell us, the number of such people with truly intractable and untreatable pain is in fact rather low. Adequate analgesia is apparently possible in the vast majority of cases, provided that the physician and patient are willing to use strong enough medicines in adequate doses and with proper timing.

But, it will be pointed out, full analgesia induces drowsiness and blunts or distorts awareness. How can that be a desired outcome of treatment? Fair enough. But then the rationale for requesting death begins to shift from relieving experienced suffering to ending a life no longer valued by its bearer or, let us be frank, by the onlookers. If this becomes a sufficient basis to warrant mercy killing, now the category of euthanizable people cannot be limited to individuals...
with incurable or fatal painful illnesses with little
time to live. Now persons in all sorts of greatly
reduced and degraded conditions—from per-
sistent vegetative state to quadriplegia, from
severe depression to the condition that now most
horripies, Alzheimer’s disease—might have equal
claim to have their suffering mercifully halted.
The trouble, of course, is that most of these peo-
iple can no longer request for themselves the dose
of poison. Moreover, it will be difficult—if not
impossible—to develop the requisite calculus of
degradation or to define the threshold necessary
for ending life.

FROM VOLUNTARY TO INVOLUNTARY

Since it is so hard to describe precisely and
“objectively” what kind and degree of pain,
suffering, or bodily or mental impairment, and
what degree of incurability or length of anticip-
pated remaining life, could justify mercy kill-
ing, advocates repair (at least for the time being)
to the principle of volition: The request for
assistance in death is to be honored because it is
freely made by the one whose life it is, and who,
for one reason or another, cannot commit sui-
cide alone. But this too is fraught with diffi-
culty: How free or informed is a choice made
under debilitated conditions? Can consent long
in advance be sufficiently informed about all the
particular circumstances that it is meant pros-
tpectively to cover? And, in any case, are not
such choices easily and subtly manipulated,
especially in the vulnerable? Kamisar is very
perceptive on this subject:

Is this the kind of choice, assuming that it can
be made in a fixed and rational manner, that
we want to offer a gravely ill person? Will we
not sweep up, in the process, some who are not
really tired of life, but think others are tired of
them; some who do not really want to die, but
who feel they should not live on, because to
do so when there looms the legal alternative
of euthanasia is to do a selfish or a cowardly
act? Will not some feel an obligation to have
themselves “eliminated” in order that funds
allocated for their terminal care might be bet-
ter used by their families or, financial worries
aside, in order to relieve their families of the
emotional strain involved?

Even were these problems soluble, the insist-
ence on voluntariness as the justifying principle
cannot be sustained. The enactment of a law
legalizing mercy killing on voluntary request
will certainly be challenged in the courts under
the equal-protection clause of the Fourteenth
Amendment. The law, after all, will not legalize
assistance to suicides in general, but only mercy
killing. The change will almost certainly occur
not as an exception to the criminal law proscrib-
ing homicide but as a new “treatment option,”
as part of a right to “A Humane and Dignified
Death.” Why, it will be argued, should the
comatose or the demented be denied such a right
or such a “treatment,” just because they cannot
claim it for themselves? This line of reasoning
has already led courts to allow substituted judg-
ment and proxy consent in termination-of-
treatment cases since Quinlan, the case that,
Kamisar rightly says, first “badly smudged, if it
did not erase, the distinction between the right
to choose one’s own death and the right to
choose someone else’s.” When proxies give
their consent, they will do so on the basis not of
autonomy but of a substantive judgment—
namely, that for these or those reasons, the life
in question is not worth living. Precisely because
most of the cases that are candidates for mercy
killing are of this sort, the line between volun-
tary and involuntary euthanasia cannot hold,
and will be effaced by the intermediate case of
the mentally impaired or comatose who are
declared no longer willing to live because some-
one else wills that result for them. In fact, the
more honest advocates of euthanasia openly
admit that it is these nonvoluntary cases that
they especially hope to dispatch, and that their
plea for voluntary euthanasia is just a first step.
It is easy to see the trains of abuses that are
likely to follow the most innocent cases, especially because the innocent cases cannot be precisely and neatly separated from the rest.

**Damaging the Doctor-Patient Relationship**

Abuses and conflicts aside, legalized mercy killing by doctors will almost certainly damage the doctor-patient relationship. The patient’s trust in the doctor’s wholehearted devotion to the patient’s best interests will be hard to sustain once doctors are licensed to kill. Imagine the scene: You are old, poor, in failing health, and alone in the world; you are brought to the city hospital with fractured ribs and pneumonia. The nurse or intern enters late at night with a syringe full of yellow stuff for your intravenous drip. How soundly will you sleep? It will not matter that your doctor has never yet put anyone to death; that he is legally entitled to do so—even if only in some well-circumscribed areas—will make a world of difference.

And it will make a world of psychic difference too for conscientious physicians. How easily will they be able to care wholeheartedly for patients when it is always possible to think of killing them as a “therapeutic option”? Shall it be penicillin and a respirator one more time, or perhaps just an overdose of morphine this time? Physicians get tired of treating patients who are hard to cure, who resist their best efforts, who are on their way down—“gorks,” “gomers,” and “vegetables” are only some of the less than affectionate names they receive from the house officers. Won’t it be tempting to think that death is the best treatment for the little old lady “dumped” again on the emergency room by the nearby nursing home?

Even the most humane and conscientious physician psychologically needs protection against himself and his weaknesses, if he is to care fully for those who entrust themselves to him. A physician friend who worked many years in a hospice caring for dying patients explained it to me most convincingly: “Only because I knew that I could not and would not kill my patients was I able to enter most fully and intimately into caring for them as they lay dying.” The psychological burden of the license to kill (not to speak of the brutalization of the physician-killers) could very well be an intolerably high price to pay for physician-assisted euthanasia, especially if it also leads to greater remoteness, aloofness, and indifference as defenses against the guilt associated with harming those we care for.

The point, however, is not merely psychological and consequentialist: It is also moral and essential. My friend’s horror at the thought that he might be tempted to kill his patients, were he not enjoined from doing so, embodies a deep understanding of the medical ethic and its intrinsic limits. We move from assessing the consequences to looking at medicine itself...
Can wholeness and healing ever be compatible with intentionally killing the patient? Can one benefit the patient as a whole by making him dead? There is, of course, a logical difficulty; how can any good exist for a being that is not? “Better off dead” is logical nonsense—unless, of course, death is not death at all but instead a gateway to a new and better life beyond. But the error is more than logical: to intend and to act for someone’s good requires his continued existence to receive the benefit.

Certain attempts to benefit may in fact turn out, unintentionally, to be lethal. Giving adequate morphine to relieve the pain of the living presupposes that the living still live to be relieved. This must be the starting point in discussing all medical benefits: no benefit without a beneficiary.

To say it plainly, to bring nothingness is incompatible with serving wholeness: one cannot heal—or comfort—by making nil. The healer cannot annihilate if he is truly to heal. The boundary condition, “No deadly drugs,” flows directly from the center, “Make whole.”

But there is a difficulty. The central goal of medicine—health—is, in each case, a perishable good: Inevitably, patients get irreversibly sick, patients degenerate, patients die. Unlike—at least on first glance—teaching or rearing the young, healing the sick is in principle a project that must at some point fail. And here is where all the trouble begins: How does one deal with “medical failure”? What does one seek when restoration of wholeness—or “much” wholeness—is by and large out of the question? . . .

Although I am mindful of the dangers and aware of the impossibility of writing explicit rules for ceasing treatment—hence the need for prudence—considerations of the individual’s health, activity, and state of mind must enter into decisions of whether and how vigorously to treat if the decision is indeed to be for the patient’s good. Ceasing treatment and allowing death to occur when (and if) it will seem to be quite compatible with the respect that life commands for itself.

Ceasing medical intervention, allowing nature to take its course, differs fundamentally from mercy killing. For one thing, death does not necessarily follow the discontinuance of treatment; Karen Ann Quinlan lived [nearly] ten years after the court allowed the “life-sustaining” respirator to be removed. Not the physician, but the underlying fatal illness becomes the true cause of death. More important morally, in ceasing treatment the physician need not intend the death of the patient, even when the death follows as a result of his omission. His intention should be to avoid useless and degrading medical additions to the already sad end of a life. In contrast, in active, direct mercy killing the physician must, necessarily and indubitably, intend primarily that the patient be made dead. And he must knowingly and indubitably cast himself in the role of the agent of death. . . .

The enormous successes of medicine these past fifty years have made both doctors and laymen less prepared than ever to accept the fact of finitude. Doctors behave, not without some reason, as if they have godlike powers to revive the moribund; laymen expect an endless string of medical miracles. It is against this background that terminal illness or incurable disease appears as medical failure, an affront to medical pride. Physicians today are not likely to be agents of encouragement once their technique begins to fail.

It is, of course, partly for these reasons that doctors will be pressed to kill—and many of them will, alas, be willing. Having adopted a largely technical approach to healing, having medicalized so much of the end of life, doctors are being asked—often with thinly veiled anger—to provide a final technical solution for the evil of human finitude and for their own technical failure: If you cannot cure me, kill me. The last gasp of autonomy or cry for dignity is asserted against a medicalization and institutionalization of the end of life that robs the old and the incurable of most of their autonomy and dignity: Intubated and electrified, with bizarre mechanical companions, helpless and regimented, once proud and independent people find themselves cast in the roles of passive,
obedient, highly disciplined children. People who care for autonomy and dignity should try to reverse this dehumanization of the last stages of life, instead of giving dehumanization its final triumph by welcoming the desperate goodbye-to-all-that contained in one final plea for poison.

NOTES

1. Of course, any physician with personal scruples against one or another of these practices may “write” the relevant exclusions into the service contract he offers his customers.


3. The inexplicable failure of many physicians to provide the proper—and available—relief of pain is surely part of the reason why some people now insist that physicians (instead) should give them death.

4. This was the title of the recently proposed California voter initiative that barely failed to gather enough signatures to appear on the November 1988 ballot. It will almost certainly be back.

FOCUS ON THE FUTURE

Neighborhood Suicide Clinics?

Imagine that it’s the year 2020. Assume that you’re having a conversation with your cousin Michael, who has spent the past three years in a remote rural village in Central Africa, working on village agriculture projects for the Agency for International Development. He’s just gotten back to the United States, and on the way from the airport, he asks you about something new he’s noticed—signs for local “Suicide Clinics.”

“What are these places, anyway?” asks Michael, in shock.

“I guess you’ve been a little out of touch,” you reply. “These clinics offer assisted suicide or euthanasia on demand. They provide a public service.”

Michael is astonished. “How is that possible? When did they get started?”

“You remember that a long time ago, the courts ruled that everyone has a constitutional right to assisted suicide? Later rulings expanded on that idea and opened up federal funding for life termination. Soon entrepreneurs moved in to fill the need. There are over 50,000 suicides each year now. It’s a growing market, and funded by Medicaid.”

“I thought that sort of thing happened in hospitals, in intensive care units?”

“Oh, it still does, lots of times, and in nursing homes, too. Many of those people are better off dead. But what about people who aren’t institutionalized? The idea is that everyone should have a right to death with dignity and have access to professional suicide services. People who are unhappy nowadays find these clinics a godsend. You know, if you don’t have good alternatives, ending your life can be the best thing. Anyway, everybody has a right to decide for themselves.”

“Why doesn’t the regular health care system handle this new service?”

“Well, some doctors do it, and insurance companies naturally pay for it because it keeps their costs down. But the medical establishment has never been keen on euthanasia: It looks bad for business. So a specialist group has taken up end-of-life practice. Remember back in the 1990s
when Dr. Jack Kevorkian was hooking people up to his ‘suicide machine’? He's the one who had the original idea: specialists in end-of-life practice.”

“There are enough people who want to kill themselves to justify a new medical specialty like that?”

“Oh, you'd be surprised, especially when you include executions. Thousands of people every year are being executed by lethal injection since the new Omnibus Capital Punishment Law went into effect. Most physicians didn't want to have anything to do with executions or killing patients, so a specialty group started up. Those doctors got in early as investors with the Thanatos Corporation, which franchises most of the suicide clinics. Those early investors made a killing, so to speak.”

“But what about people who really shouldn't be ending their lives?”

“Well, it's 'buyer beware' in the marketplace, you know. Nobody forces anyone to go. Anyway, people would rather make these decisions instead of letting the government decide for them.”

“What about people who are mentally ill?”

“Oh, the clinics don't discriminate against them. Discrimination against the mentally ill is against the law. There was a big court case on that issue two years ago. If you're mentally ill, you have the same right to use suicide services as anyone else. Well, welcome back to the United States, Michael.”

### Questions for Writing, Reflection, and Debate

1. Are McKhann's reasons for a physician to help a terminally ill patient die convincing? Would exactly the same reasons apply if the patient were not terminally ill, but instead were suffering from a chronic condition—for example, the aftereffects of a stroke—that diminished the quality of life?

2. Advocates for physician-assisted suicide generally believe that if a person is depressed and not rational, others should not help to end that person's life. Is it possible for someone to be deeply gloomy about life yet still be rational and therefore rationally decide to commit suicide? Imagine that you have just received a letter from an older friend expressing such gloomy thoughts in favor of suicide. Write a detailed response giving your reasons for agreeing or disagreeing with the conclusions reached.

3. Is there really a difference between a doctor going along with a request to terminate treatment that will result in a patient’s death and a doctor intentionally giving a deadly drug? What about the case of withdrawing artificial nutrition or hydration from a patient?

4. Leon Kass offers a “slippery slope” argument against allowing doctors to engage in mercy killing. That is, Kass believes that, once we set a precedent and get used to the idea of deliberate killing, we will have no way to stop the practice from expanding. Is Kass’s fear of the danger a realistic one, or is it exaggerated? What steps could be taken to avoid the dangers?

5. Look carefully at the different decisions that Woodman's older “Aunty” makes at various times over the course of her last illness. She changes her mind and sometimes says contradictory things. In your view, does this fact suggest that advance directives aren’t useful in cases like hers? How big a problem would this be for people in general?

6. Assume that your employer, the chief administrator of a nursing home, has asked you to draft a statement of policy expressing what the nursing home should do when a resident says he or she no
longer wants to go on living. In developing your policy statement, be sure to give guidance to doctors, nurses, and social workers on how they should act when they come in contact with such a situation.

7. Visit the website for the Euthanasia Research & Guidance Organization at www.assistedsuicide.org. If you are worried about the suicide rate among older people, can you find anything to criticize in the material available on this site?

Suggested Readings


Byock, I., *The Best Care Possible: A Physician’s Quest to Transform Care Through the End of Life*, New York: Avery Trade, 2013.


Student Study Site

Visit the Student Study Site at [http://study.sagepub.com/moody9e](http://study.sagepub.com/moody9e) for these additional learning tools:

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