

1 Biology of Aging

Teresa Dolinar

Aging is a complex developmental process that is, as yet, poorly understood. From a physical perspective, aging involves a loss of resilience or reserve capacity to respond to stressors, and this acquired vulnerability usually means that aging is associated with some greater susceptibility to illness as well as some decline in function over time. Nevertheless, the effects of aging are highly variable; some men and women are still running races at the age of 82, while others are frail and bed-bound in a nursing home. In this brief overview, the physiology of aging in the major organ systems, what is known about the human life span, and different theories of aging are outlined.

Physiology of Aging

We have learned a great deal about aging physiology and which biological parameters change with age through the Baltimore Longitudinal Study on Aging, sponsored by the National Institute of Aging (NIA). This study has tracked a group of older persons for about half a century. It confirms that the most important physiological changes that accompany the aging process may relate primarily to disease susceptibility. Some clinical measures, such as laboratory tests for anemia or liver functioning, remain consistent for early and later adulthood. Nevertheless, there are patterns associated with aging in the various systems of the body, as described below.

Cardiovascular System

The cardiovascular system involves the heart and the blood circulatory pathways (e.g., arteries and veins) in the body. The heart rate at rest is generally unchanged with age. However, there is a reduced maximal heart rate in response to exercise among elderly subjects. This occurs even in older persons who are aerobically fit and have no evidence of underlying cardiac disease. Thus, the 82-year-old master athlete will likely run a marathon more slowly than he did in his younger years. Although his ability to pump blood throughout his body is unchanged when he is resting, he cannot reach the levels of cardiac output while running that he once did.

The left ventricle of the heart fills more slowly in older persons and becomes stiffer; this predisposes aging adults to heart failure. Older persons are more at risk of becoming overloaded with fluids (“volume overload”) when they have excess salt in their diets or when their blood pressure is uncontrolled. In addition, there is an increased stiffness of the blood vessels with aging, as the walls of the major arteries thicken and lose their elasticity. This greater rigidity predisposes older persons to increased blood pressure and to atherosclerosis. It also decreases the responsiveness of the automatic mechanisms in the body that help regulate blood pressure. These alterations, combined with a decreased ability to achieve a more rapid heart rate when needed, make older persons more susceptible to drops in their blood pressure (“hypotension”), e.g., when they are dehydrated.

Respiratory System

With age, the chest wall stiffens, which affects the compliance and elasticity of the lungs. Further contributing factors are osteoarthritis of the spine and calcification of the cartilages of the rib cage. Thus, a 70-year-old “healthy” man has about 50% of the lung function of a 30-year-old man, who himself is probably at the peak of his lung functioning. The energy expenditure of breathing is increased, although the lungs maintain adequate exchange of oxygen and carbon dioxide. There is only a slight decrease in the concentration of oxygen in the arteries of older adults (Janssens 2005).

In normal aging, these changes cause less respiratory “reserve” and make older persons more likely to experience shortness of breath with any illness. Older persons are also more susceptible to severe respiratory consequences from the same influenza viral infection that may cause only minor illness in younger family members. This increased susceptibility to morbidity from respiratory illness is the reason why physicians target older persons for influenza and pneumococcal vaccinations.

Renal and Urinary Systems

One of the most clinically significant changes in older adults is a decline in ability to maintain salt and water balance in response to stress (Hodak and Verbalis 2005). Maintaining this balance is an important function of the kidneys. Blood volume in the human body is already decreased with aging. The older kidney loses its ability to concentrate urine in response to acute volume losses, such as bleeding in the gastrointestinal tract or dehydration. This may be coupled with a decrease in the sensation of thirst, as the special nerve endings (“osmoreceptors”) that help regulate this function are less robust in signaling to the brain to initiate water-seeking behavior. Therefore, a 90-year-old woman who begins vomiting from a viral gastroenteritis is more likely to become dehydrated and develop acute renal failure from the illness than her 30-year-old counterpart. This older patient is also more likely to be admitted for hypernatremia, or increased sodium levels in the blood. The proportion of sodium and other elements of blood (“electrolytes”) is delicate, and disturbance of this balance may create increased risk of mortality from a viral illness that is usually self-limited in younger persons.

With age, there is also a loss of the diluting capacity of the kidney and a reduction in the ability to excrete excess water in the face of fluid overload. This makes management of an older person, who requires intravenous (IV) fluids for dehydration, more difficult than that of a younger person. This loss in dilutional capacity of the kidney is partially due to a decline in the filtration ability of the kidney. This decline does not seem to occur inevitably with aging, but does seem to occur in about 70% of persons after the age of 65. This change also affects the metabolism of drugs that are cleared by the kidney.

The capacity of the bladder decreases with age, and so older persons are less able to hold their urine voluntarily. This problem is compounded by enlargement of the prostate in older men, which also contributes to the urgency of voiding. The force of bladder contractility declines, so that more urine remains in the bladder of both men and women after voiding. This predisposes both sexes to an increased incidence of urinary tract infections. Older women are also more susceptible to infections because of thinning of the vaginal wall and the tissues of the urethra after menopause. Interestingly, older persons also tend to produce more urine at night, which is thought to be related to changes in the daily rhythm of hormones (antidiuretic hormone or ADH) that help regulate urine production.

Endocrine System

The endocrine system refers to the body’s hormonal production and regulation. Much attention has been focused on the hormonal changes that occur with aging. There is a decline in growth hormone (GH) levels among elderly persons, with a decline in both GH secretion and serum GH concentration. This decline in GH is thought to contribute to a decrease in lean body mass and muscle strength, a thinning of the skin and bones, and an increase of fat in older adults. Studies have shown conflicting results as to whether replacement of GH in older persons can lead to permanent reversal of these changes without untoward side effects.

Insulin resistance increases with age, so that older persons are more likely to present with hyperglycemia with acute illness, even if they were not previously known to be diabetic. This insulin resistance with aging seems to be independent of the degree of body fat or physical activity. Parathyroid hormone levels increase with age, making older persons more susceptible to hypercalcemia. There is no decline with age in serum total or free thyroxine concentrations. Thyroxine clearance does decrease with age, and this is why older patients with hypothyroidism often require lower starting doses of thyroid-replacement therapy.

Dehydroepiandrosterone (DHEA) is a hormone that decreases with aging. DHEA is produced by the adrenal cortex, and although its function in the body is unclear, it appears to be a chemical compound needed in the production of androgens and estrogens, the major sex hormones. Yet, researchers are studying it closely. In 80-year-old men and women, the serum concentration of DHEA is only 20% of that seen in 20-year-olds. Its effect on aging is unknown, and studies have shown some potential adverse effects with supplementation.

Skin

The skin is a very important “system” of the body. With age, there is a thinning of the epidermis and dermis, with wrinkling and increased laxity of the skin. This is independent of ultraviolet light exposure. There is also decreased vascularity of the skin. These changes make the skin more susceptible to friction injury and shearing forces, sometimes leading to “skin tears” as a result of minimal trauma in frail older persons. There is a decrease in the healthy turnover of the outer layer of the skin (the “epidermis”) and as a result, skin tends to be drier, with itching and cracking more common. Hair grows more slowly. Graying of hair is variable but does occur in all persons to some extent, as the number of melanocytes in hair bulbs decreases over time. There is a loss of subcutaneous fat, which may contribute to greater susceptibility to deep sores (decubitus ulcers) over pressure points such as the sacrum and heels.

Gastrointestinal System

The lining of the stomach secretes less acid with age, but this does not appear to affect digestion. Associated thinning of the gastric mucosa may decrease absorption of nutrients, making B12 vitamin deficiency more common with age. There is often a change in the timing and coordination of swallowing (“esophageal motility”), which may predispose to pill-induced esophagitis. Colonic function also declines so that older persons are more likely to experience constipation.

Brain and Sensory Systems

There is a slight shrinking of the brain with aging. Thus, on brain imaging, it is common to see some degree of cerebral atrophy in those who are over 80 years of age.

Additionally, there is a decline in sleep efficiency with aging, which is described as the ratio of time spent asleep to time in bed. Insomnia is thus a common complaint of the elderly. Multiple awakenings at night, some of which can be prolonged, are common.

Thermoregulation, the body’s maintenance of a constant body temperature, is altered with age, increasing the risk of both hypo- and hyperthermia. Older persons have decreased sweating also, which predisposes them to severe consequences of extreme temperatures.

Vision and hearing are likely to decline with aging. For instance, there are changes in the lens of the eye with age, as there are modifications in lens proteins. This leads to a thicker and more opaque lens, what can become clinically symptomatic as a cataract. Sensitivity to sound (i.e., auditory stimuli), especially in certain ranges, may decline, although these changes may be amenable to intervention and should be carefully evaluated.

In the sixth and seventh decades, there is a sharp decline in the sense of smell. The cause of this is multifactorial as the cells and cilia of the olfactory epithelium decrease in number and function (Seiberling 2004). Taste is also affected with age, but anatomic changes are less impressive, and may be related to changes in the taste cell membrane rather than to loss of taste buds. There is a greater reduction in the ability to detect salty/bitter tastes than sweet tastes. Older persons may therefore tend to add more salt to foods, which may in turn exacerbate hypertension or congestive heart failure.

Musculoskeletal System

Lean muscle mass and strength declines by the fourth decade. This has been demonstrated by cross-sectional imaging with CT scan. By the age of 70, muscle mass declines by about 25%, unless resistance training and exercise combats the decline.

Bone mass decreases with age, after reaching a maximum in the second decade. Bone loss is accelerated during menopause, when it can increase to 2–3% per year.

Life Span

Understanding the underlying physiology of aging may help practitioners to target therapies to help patients live both healthier and longer lives. It is thus important to understand the biological influences on life span.

The maximum life span is species-specific, and it is believed to represent the way in which organisms balance their ability to survive and reproduce in a competitive environment. In many organisms, this balancing act may represent what some biologists feel are evolutionary pressures for a minimally successful life. Field mice live only a few days, and most die from cold exposure. These mice invest their available energies in maintaining their body temperature and reproducing to maintain their species. They do not have sophisticated DNA repair-and-maintenance mechanisms for their cells as humans do, who survive much longer. In fact, the ability to repair ultraviolet (UV) radiation to DNA is directly related to a species' maximum life span (Hart and Setlow 1974).

The longest living human on record is now recognized to be Madame Jean Calment of France, who died at the age of 122 years in 1997. Average life expectancy has increased dramatically over time, gaining nearly 30 years in the past century. In 1900, the average life expectancy was less than 50 years. Today it stands at 77 years (see [Table 1](#)). The most dramatic advance occurred because of improvements in sanitation and the treatment of infections. Advances in treatment of cardiovascular disease caused gains during the past decade.

Table 1
Expectation of life at birth

Year	Average expectation of life (years)
1970	70.8
1980	73.7
1990	75.4
2000 (projected)	77.1
2010 (projected)	78.5

Source: U.S. Census Bureau, Population Division, Working Paper No.38. U.S. Center for Vital Statistics of the United States, Annual, and National Vital Statistics Reports (NSVR).

But can this trend continue? Experts project that the maximum life span will remain at 90–100 years. Even if we eliminated the top 10–15 causes of death, including cardiovascular disease, cancer, and kidney disease, demographers feel that we would not gain more than another 20 years of life expectancy. The rate of infant mortality will not decline, because of congenital disease and accidental death, and to reach an average life expectancy of 100 years, experts feel would require the elimination of all mortality before the age of 85 (Kinsella 2005).

Research has given some interesting clues about how the human life span may be lengthened. One of the interventions known to reliably extend life span in animal models ranging from *Drosophila* flies to primates, such as the rhesus monkey, is calorie restriction (CR). What is meant by CR is underfeeding without malnourishment. Most studies involved severely restricting calories (up to 40% of what animals would eat freely), while still providing essential minerals and vitamins. CR can increase both the average and maximum life spans of mice and

rats by more than 50% (Weindruch and Walford 1988). Even more important perhaps is the fact that CR seems to delay physiological and pathological changes usually seen with aging. Diet-restricted animals show less aging in hormonal, immune, and cardiac function and less cancer than animals that are allowed to eat freely. They do, however, show a decrease in reproductive abilities.

The underlying mechanism for the increase in life span is not entirely clear, and likely represents how inherent genetic/developmental determinants can be manipulated by environmental factors. It likely represents an interaction of changes at the molecular, cellular, and system levels. It does not seem to be related only to an alteration in metabolic rate (McCarter and Palmer 1992). The model of CR may also help to demonstrate how many of the theories of aging overlap. Genetic theory may be involved. When gene expression is compared in calorie-restricted animals and normally fed animals, there are a number of genes that show altered expression (Koubava and Guarente 2003). Some of these genes likely affect the insulin growth factor-1 (IGF-1) pathways. The oxidative stress theory may also help explain the benefits of CR (Sohal and Weindruch 1996). There is some evidence that oxygen consumption is lowered by CR, thus oxidative stress is lowered and there is less production of reactive oxygen species (ROS). This leads to less cellular damage and cross-linking of proteins. Hormonal factors may also be involved, as there is evidence that GH levels may be affected by CR.

There are ongoing studies in rhesus monkeys on the physiological effects of CR (Roth 2005). There is even NIA sponsored research with trials of CR (20–30% reduction) in young and middle-aged persons to see the effects on aging in humans.

Theories of Aging

Given that aging is complex, there exist many theories that attempt to explain the concept (see [Table 2](#)). Animal models have served as the basis for much of what is currently known about the aging process. Not one unifying

Table 2

Selected theories of aging

Evolutionary	
Disposable soma	Selective pressures for reproduction; body is disposable once this occurs
Antagonistic pleiotropy	Antagonism between genes beneficial for reproduction but not for longevity
Molecular	
Genetic	Changes in gene expression affect longevity and aging
Somatic mutation	Damage occurs to DNA over time, affecting transmission of genetic material
Cellular	
Wear and tear	Damage accumulates to cells over time
Free radicals	Oxidative metabolism produces free radicals toxic to DNA and proteins
Telomere shortening	Shortening of telomeres with time permanently affects cell division (senescence)
System	
Neuroendocrine	Master biological clock controls hormones and body's ability to react to stress
Immune	Immune function declines with age, increasing risk of cancer and infection

theory for the mechanism of aging exists, and the translation from short-lived animal models to human models is not ideal. Aging involves changes at the molecular, cellular, and system levels and is influenced by developmental, environmental, and “chance” factors.

Genetic Theory

Is longevity genetically based? The fact that longevity is species-specific seems to support an underlying genetic component. Centenarians are currently being studied by researchers to unravel the mystery of longevity, as their

siblings and children are also likely to live longer. If the reason why siblings of centenarians are much more likely to live to age 100 themselves was entirely due to socioeconomic or environmental factors, that advantage should decline with age (Perls and Dellara 2003).

In animal models such as the nematode and the *Drosophila* fly, single-gene mutations have been associated with longevity. There is a line of *Drosophila* with a specific gene mutation nicknamed “Methuselah” (Lin et al. 1998), which show an approximately 35% increase in average life span. They also show an increased resistance to stress, including starvation and higher temperatures. In mice, there seems to be a link between longevity and genes that encode for a hormone, IGF-1, which is an insulin-like hormone that influences the rate of growth. Lower levels of IGF-1 seem to be associated with longevity in multi-model systems. In mice, the shorter, smaller, lighter-weight animals are the ones that live the longest. Mice with higher levels of IGF-1 die younger, and tend to be heavier and larger animals at 3 months of age (Miller 2005). Shutting off insulin-signaling pathways in nematodes also makes them live longer (Kimura et al. 1997).

Are there human longevity genes? There is an ongoing New England Centenarian Study that includes genome studies to look at links for genes that may be associated with longevity in centenarians and their families. There does seem to be a locus on chromosome 4 that is common to many long-lived families, but studies are ongoing and attempts to replicate prior studies continue (Puca et al. 2001).

The genetic puzzle remains complicated for researchers and is unlikely to be the only underlying explanation for aging. For example, baboons and humans share about 97% of their genes, yet baboons live for about 20 years and humans about 80 years. Experts foresee that what we have learned about genes and longevity is unlikely to lead to gene therapy or other types of genetic manipulation to extend life. Instead, it is likely to help provide clues about how the cells of our bodies work. We are more likely to use this knowledge to design drug therapies that might slow down the process of aging (Miller 2005).

DNA Maintenance and Repair Mechanisms

Some “evolutionary” models of aging (Kirkwood 1988) focus on the balance that must exist between the need of a species to reproduce and the disposability of the organism once this occurs (Disposable Soma Theory). For example, the cells of the human body accumulate damage to their DNA over time, and humans must invest some energy into maintenance-and-repair mechanisms. Despite these attempts at repair mechanisms, damage eventually accumulates in key molecules in the cell. This causes some cells to permanently stop dividing, a term called senescence. Some say that this process is ultimately protective, as abnormal cells cannot survive and replicate to produce a cancer (Campisi 2005). This process may be genetically driven, so that some genes guide early reproduction and are advantageous in early life, but can be “pro-aging” to prevent cancer later on. This is a concept referred to by the term “antagonistic pleiotropy.”

Free Radical Theory

A specific form of the “wear and tear” theory, where accumulated debris in cells leads to their malfunction and death, is the free radical theory. This theory was first proposed by Harman (1956). The mitochondria, where energy is produced in human cells, produce vital energy. However, this process is tied to the production of what is termed ROS. These are unstable compounds, such as superoxide or hydroxyl radicals, that can combine with cell components and lead to damage to DNA and proteins (Finkel and Holbrook 2000). Species with longer life spans produce more superoxide dismutase, an enzyme that inactivates ROS.

One of the specific ways ROS cause damage is by producing cross-linking of proteins. These cross-links increase with age and alter especially long-lived proteins such as collagen and elastin, which can lead to stiffening of the arteries and heart (Lakatta and Levy 2003a, b). Cross-linked proteins are often not functional and cannot be cleared by the usual system for dealing with damaged protein in the cell. Thus, they accumulate and can contribute to damage or disease. One specific example of cross-linking is the reaction between glucose in cells

and an amino group found in proteins, a process known as “glycation.” One of the underlying theories for why diabetic patients show premature aging is that hyperglycemia or increased sugar levels leads to increased ROS in the cells that line the aorta and thus causes premature atherosclerosis.

Cellular Aging and Senescence

A recurring theme in aging is maintenance and repair, and this goes on also at the cellular level. Cell turnover is a way of ensuring healthy cells. However, normal human cells will not divide forever, even in culture in the laboratory. After a defined number of cell divisions, cells enter a non-dividing state termed senescence. Thus, cells seem to be able to “count” the number of their divisions rather than the time that passes.

What is responsible for this process? Is there a master biological clock? Some feel that what may be responsible for this counting mechanism are telomeres and their process of shortening over time. Telomeres are caps at the end of chromosomes that become shorter with every cell division. This process is what is thought to keep human cells from becoming immortal and from dividing indefinitely in culture. This is thought to take place because, after a defined number of cell divisions, critically shortened telomeres generate a “DNA-damage signal,” which causes the cell to enter senescence (Wright and Shay 2005).

There is, however, a mechanism to counteract this process by an enzyme called telomerase, which is able to “add back” parts of telomeres that are lost. Telomerase is turned off in most cells of the body early on in life so that they are not immortal. Cells meant to keep dividing, such as stem cells of the bone marrow, do have active telomerase. In the 1990s, it was discovered that introducing telomerase into non-stem cells of the human body could make them immortal in cell culture (Bodnar et al. 1998).

Cancer cells, in nearly 90% of cases, show abnormal expression of telomerase, and this is thought to be one of the underlying reasons why the abnormal cancer cells can survive and replicate. Introducing telomerase into normal cells does not, however, turn them into cancer cells.

Higher levels of telomerase expression in cancer cells correlate with a worse clinical prognosis. One of the challenges for researchers is to find ways to inhibit telomerase in cancer cells, as this may ultimately make cancer cells more responsive to chemotherapy and other anti-cancer therapies (Wright and Shay 2005).

Telomere length may also correlate with human longevity. A study looking at telomere length in peripheral blood smears showed that longer telomeres were associated with a lower risk of death (Cawthon et al. 2003).

Telomeres shorten not only with cell replication, but can also shorten with oxidative stress (Von Zglinicki 2002). This serves as one example of how multiple theories of aging interact. Another example is demonstrated by how telomere activity may be modulated by genes. The *p53* gene may be a mechanism for “controlling” cell senescence. It is an example of “antagonistic pleiotropy,” as it may be “anti-tumor” early on in life (thought in the evolutionary sense to promote reproduction) and “pro-aging” later on. In mice models, too little *p53* expression results in death from cancer early on (Chin et al. 1999). Too much *p53* gene expression results in accelerated aging with development of premature osteoporosis, weight loss, and decreased wound healing (Tyner et al. 2002). This again demonstrates the theory that cell senescence may actually be protective, and aging may be the price that we pay to avoid cancer (Campisi 2005).

Cell Death: Necrosis and Apoptosis

While cellular senescence, or a permanent withdrawal from cell division, may be a mechanism to prevent the development of cancer, cell death may represent another way in which the body protects itself from abnormal cells. Cell death can take two forms including necrosis and apoptosis (Kumar et al. 2005). Necrosis is thought to result from massive cell injury that is accidental and is always pathological. An example would be when cells of the heart muscle undergo necrosis because of ischemia, or lack of blood flow, during a myocardial infarction. Apoptosis is more of a controlled cell death, what some call “programmed” cell death, in response to a stimulus. It is thought to be genetically driven. In contrast to necrosis, apoptosis is thought to be physiological, and may be

a means of ridding the body of unwanted cells. An example of this is seen in the immune system, whereby T lymphocytes undergo cell death in what is thought to be a reaction to the recognition of self-antigens that might cause autoimmune diseases (Troen 2003). Death of neuronal cells is seen in many degenerative diseases, including Alzheimer's disease.

Neuroendocrine/Immune Theory

Some biologists feel that the nervous, endocrine, and immune systems coordinate all the other systems in the body, and that aging is tied to an overall declining ability to deal with stressors (McEwen 2003). Some believe that the master "biological clock" is ultimately in the hypothalamus in the brain, and that it is responsible for aging through hormonal pathways. There are decreases in hormones with normal aging, most notably the reproductive hormones such as estrogen and testosterone. There are also decreases in growth factors and in secretions of other hormones that affect the older individual's ability to deal with stressors such as infection or dehydration.

There is evidence that immune function declines with age. The function of T lymphocyte cells declines, increasing the chances of developing infection and cancer. This may be caused by an alteration in cytokines, which are molecules responsible for communication between immune cells.

Models of Premature Aging

There are examples of premature aging in humans that may teach us about the biology of aging. The term progeria literally means "premature aging."

Werner's Syndrome

In Werner's syndrome or "adult progeria," features of aging are first seen at puberty. Usually, affected children are of normal height in elementary school, but then fail to have an adolescent growth spurt. They develop many features typical for aging early on in life. They develop early cataracts, although not in the same part of the lens of the eye usually seen in older persons. They have typical skin changes with aging, such as tightening and skin fragility, and graying and thinned hair. They usually suffer from osteoporosis, early menopause, myocardial infarctions, diabetes mellitus, and cancer. Death is usually from a myocardial infarction or cancer, at a median age of 47 years. Interestingly, they do not usually develop Alzheimer's disease or hypertension.

Werner's syndrome is an autosomal-recessive condition and the gene responsible lies on chromosome 8. It is thought to be from a single gene mutation of a DNA helicase, an enzyme thought to be involved in "unwinding" DNA (Gray et al. 1997). The DNA repair process appears to be normal, but initiation of DNA synthesis seems to be defective. Cells show normal length of telomeres but accelerated telomere shortening (Martin 2005).

Hutchinson–Gilford Syndrome

Classic "progeria" or Hutchinson–Gilford (HG) syndrome is a very rare condition that affects one-eighth million births (Sarkar and Shinton 2001). It is a syndrome of premature aging that begins within the first 2 years of life. Affected persons suffer from wrinkled skin, stooped posture, and growth retardation. They have absent sexual maturation but normal mental development. They have advanced atherosclerosis and usually die from a myocardial infarction by the age of 30, with an average life span of 12 years. Interestingly, unlike Werner syndrome patients, they do not usually develop cataracts, diabetes, or skin ulcerations. Like patients with Werner's syndrome, they also do not develop Alzheimer's disease, but do develop premature atherosclerosis. Therefore, both syndromes may offer clues to studying atherosclerosis.

Cells of patients with HG have shorter telomeres, and so they may have a shortened cellular “master clock.” Thus, their cells demonstrate a reduced ability to replicate and may allow DNA damage to remain un-repaired (Ahmed and Tollefsbol 2001).

Down Syndrome

Patients with Down syndrome also demonstrate premature aging. Down syndrome is secondary to a trisomy or a translocation on chromosome 21. Patients with Down syndrome often experience early vascular disease, diabetes, hair loss, osteoarthritis, and an increased incidence of cancer. Early dementia, in contrast to patients with Werner’s syndrome and HG, does occur in patients with Down syndrome. They have pathological changes in their brains similar to those that are seen in older patients with Alzheimer’s disease. This may be secondary to the fact that the B-amyloid gene is present on chromosome 21, which has been associated with the plaques and tangles typically seen on pathology in the brains of patients with Alzheimer’s disease.

Conclusions

Research into the biology of aging tends to focus on single mechanisms for aging. No theory clearly explains why some age successfully and some do not. We do not yet know all that we can do to keep our bodies’ homeostatic mechanisms in check, to avoid frailty, disability, and disease as we age. Additionally, it is unclear how studies done on short-lived animal models will translate to longer-lived humans. Experts in the biology of aging hope to use current research knowledge to help target future interventions. This may help us not only to live longer, but to age successfully as we do.

References

- Ahmed A, Tollefsbol T (2001) Telomeres and telomerase: basic science implications for aging. *J Am Geriatr Soc* 49:1105–1109
- Bodnar AG, Ouellette M, Frolkis M et al (1998) Extension of life-span by introduction of telomerase into normal human cells. *Science* 279:349–352
- Campisi J (2005) Senescent cells, tumor suppression, and organismal aging: good citizens, bad neighbors. *Cell* 120:513–522
- Cawthon RM, Smith KR, O’Brien E, Sivatchenko A, Keiber RA (2003) Association between telomere length in blood and mortality in people aged 60 years and older. *Lancet* 361:393–395
- Chin L, Artandi SE, Shen Q et al (1999) p53 deficiency rescues the adverse effects of telomere loss and cooperates with telomere dysfunction to accelerate carcinogenesis. *Cell* 97:527–538
- Finkel T, Holbrook NJ (2000) Oxidants, oxidative stress and the biology of ageing. *Nature* 408:239–247
- Gray MD, Shen JC, Kamath-Loeb AS et al (1997) The Werner syndrome protein is a DNA helicase. *Nat Genet* 17:100–103
- Harman D (1956) Aging: a theory based on free radical and radiation chemistry. *J Gerontol* 11:298–300
- Hart RW, Setlow RB (1974) Correlation between deoxyribonucleic acid excision-repair and life-span in a number of mammalian species. *Proc Natl Acad Sci USA* 71:2169–2173
- Hodak SP, Verbalis JG (2005) Abnormalities of water homeostasis in aging. *Endocrinol Metab Clin N Am* 34:1031–1046
- Janssens J (2005) Aging of the respiratory system: impact on pulmonary function tests and adaptation to exertion. *Clin Chest Med* 26:469–484
- Kimura KD, Tissenbaum HA, Liu Y, Ruvkun G (1997) Daf-2, an insulin receptor-like gene that regulates longevity and diapause in *Caenorhabditis elegans*. *Science* 277:942–946
- Kinsella KG (2005) Future longevity—Demographic concerns and consequences. *Journal of the American Geriatrics Society* 53(9S):S299–S303
- Kirkwood TB (1988) The nature and causes of aging. *Ciba Found Symp* 134:193–207
- Koubava J, Guarente L (2003) How does caloric restriction work? *Genes Dev* 17:313–321
- Kumar V, Abbas AK, Fausto N (2005) Robbins and Cotran: pathologic basis of disease, 7th ed. W.B. Saunders, St. Louis
- Lakatta EG, Levy D (2003a) Arterial and cardiac aging: major shareholders in cardiovascular disease enterprises. Part I. Aging arteries: a “set up” for vascular disease. *Circulation* 107:139–146
- Lakatta EG, Levy D (2003b) Arterial and cardiac aging: major shareholders in cardiovascular disease enterprises. Part II. The aging heart in health: links to heart disease. *Circulation* 107:346–354
- Lin YJ, Seroude L, Benzer S (1998) Extended life-span and stress resistance in the *Drosophila* mutant Methuselah. *Science* 282:943–946

- Martin GM (2005) Genetic modulation of senescent phenotypes in *Homo sapiens*. *Cell* 120:523–532
- McCarter R, Palmer J (1992) Energy metabolism and aging: a life-long study of Fischer 344 rats. *Am J Physiol* 263:E448–E452
- McEwen BS (2003) Interacting mediators of allostasis and allostatic load: towards an understanding of resilience in aging. *Metabolism* 52(10):10–16
- Miller RA (2005) Genetic approaches to the study of aging. *J Am Geriatr Soc* 53:S284–S286
- Perls T, Dellara T (2003) Understanding the determinants of exceptional longevity. *Ann Intern Med* 139(5):445–450
- Puca AA, Daly MJ, Brewster SJ et al (2001) A genome-wide scan for linkage to human exceptional longevity identifies a locus on chromosome 4. *Proc Natl Acad Sci USA* 98:10505–10508
- Roth GS (2005) Caloric restriction and caloric restriction mimetics: current status and promise for the future. *J Am Geriatr Soc* 53: S280–S283
- Sarkar PK, Shinton RA (2001) Hutchinson–Guilford progeria syndrome. *Postgrad Med J* 77:312–317
- Seiberling KA (2004) Aging and olfactory and taste function. *Otolaryngol Clin North Am* 37:1209–1228
- Sohal RS, Weindruch R (1996) Oxidative stress, caloric restriction, and aging. *Science* 273:59–63
- Troen BR (2003) The biology of aging. *Mount Sinai J Med* 70(1): 3–22
- Tyner SD, Venkatachalam S, Choi J et al (2002) p53 mutant mice that display early ageing-associated phenotypes. *Nature* 415:45–53
- Von Zglinicki T (2002) Oxidative stress shortens telomeres. *Trends Biochem Sci* 27:339–344
- Weindruch R, Walford RL (1988) The retardation of aging and disease by dietary restriction. Charles C. Thomas, Springfield, IL
- Wright WE, Shay JW (2005) Telomere biology in aging and cancer. *J Am Geriatr Soc* 53:S292–S294

Suggested Readings

- Hadley EC, Lakatta EG, Morrison-Bogorad M, Warner HR, Hodes RJ (2005) The future of aging therapies. *Cell* 120:557–567
- Kirkwood T (2005) Understanding the odd science of aging. *Cell* 120:437–447
- Weinert BT, Timiras PS (2003) Invited review: theories of aging. *J Appl Physiol* 95:1706–1716

Suggested Resources

- Longevity Consortium, involving large-scale human studies working in collaboration with basic-science researchers in the biology of aging. www.longevityconsortium.org
- NIA-supported Baltimore Longitudinal Study on Aging. www.grc.nia.nih.gov/branches/blsa/blsa.htm

2 The History and Demography of Aging in the United States

Gail E. Souare and Linda S. Lloyd

Introduction

Aging is a natural process that begins at birth and ends at death. Society often identifies aging with disease, disability, loss of mental capacity, and the final stages of life. However, the Baltimore Longitudinal Study of Aging (BLSA) demonstrated that the previously assumed “natural decline associated with aging” is not inevitable; increased activity and other health-promoting behaviors may prevent and even reverse these effects.

Therefore, it is essential to distinguish between the true effects of aging and those processes, including disease, that may appear or become more pronounced with time but are biologically irrelevant to the underlying mechanisms of human aging. The fact that chronic debilitating conditions may be in part preventable, demands that rehabilitation specialists, and particularly rehabilitation researchers, focus their efforts on the restoration, maintenance, and promotion of a healthy lifestyle. Key elements of a healthy lifestyle may well be the maintenance of an active and involved life, particularly the promotion of exercise and good nutrition and elimination of harmful behaviors.

Defining Aging

Who is old? Specific chronological markers for old age are arbitrary. The definition of “older adult” or “senior” varies, depending on different perspectives and purposes. For example, gerontologists traditionally focus on persons aged 60 years and older. The US federal government uses the age of 65 as a marker for full Social Security and Medicare benefits, yet the US Department of Housing and Urban Development defines a senior as anyone aged 55 or older. The largest advocacy group for older adults, the American Association of Retired Persons (AARP), defines an older adult as a person aged 50 or older. Is “old” the age of retirement? If so, the Social Security Administration (SSA) defines retirement age as 62, yet full retirement is not until 65 for persons born after 1937 and it is being raised to 67 for persons born after 1959. In addition, there is no longer one category that includes all older adults. Health care providers and planners now identify subgroups of “older adults” as “younger old” (ages 65–75), “older-old” (ages 75–85), and “oldest old” (ages 85+).

Subjectively, though, many older adults do not label themselves as “old,” even at advanced ages. Studies have shown that as seniors age, they continue to grow, create, and engage in activities linked with education and travel. Some older adults are late-life career bloomers; others become active with their families or proactive in their communities. Free from work commitments, older adults are becoming invaluable to their communities as more and more volunteer their time.

Demographics and Trends of Older Adults

There is an increased awareness of the aging of America. According to the US Census Bureau, in 2002, 26.6 million men and 33.0 million women in the noninstitutionalized population were aged 55 and over. While the population of the United States has tripled in the last century, the population of Americans aged 65 and older has increased 11 times. Demographic data show that one in eight Americans is aged 65 or older; more than 35% of these seniors

are aged 75 and older. By the year 2030, seniors will comprise one in five Americans. As the Baby Boom generation grows older and Americans live longer, there is new interest in senior health care and health longevity to increase productivity, independence, and optimal health while aging. For optimal health, older adults need access to health care services, quality medical and psychosocial assessments, effective treatment plans, and culturally sensitive medical care and social programs.

The following are some important demographic data to consider when planning services for older adults and seniors:

- *Marital status:* Living arrangements and marital status of the older population differ considerably between men and women as they age. In 2002, among people 55 years and over, men were more likely than women to be married and living with their spouse (74 and 50%, respectively). Due to longer life expectancies than men, it is not surprising that 31% of women but only 9% of men aged 55 and over were widowed. With increasing age, this proportion rises rapidly: 10% of women 55–64, 41% of women 65–84, and 79% of women 85 and over were widows.
- *Education:* Among the older population, men are more likely than women to have higher levels of education. High-school completion rates vary among the older population. In 2002, 84% of people aged 55–64, 71% of those aged 65–84, and 58% of those 85 and over had completed high school.
- *Income:* Married-couple households with a member aged 55–64 are more likely to have higher incomes than those with a member 65 years or older. In 2001, 77% of married-couple households with at least one member aged 55–64 had an income of \$35,000 or more, compared with 49% of married-couple households 65 and over. Married-couple households were more likely to have an income below \$20,000 when the person was aged 65 and over than when the householder was aged 55–64 (20 and 10%, respectively).
- *Poverty:* Among people 55 years and over, those aged 65 and over are most likely to be poor. In 2001, 5.8 million (9.8%) people of 55 years and over were living below the federal poverty level. The highest rates of poverty among this group were unmarried households: 14.1% of women and 10.7% of men. This compares with a 4.8% rate of poverty for married-couple households.
- The poverty rate also increases with age. The poverty rate was 9.4% for those 55–64 and 10.1% for those 65 years and over. Older women, in general, had a higher poverty rate than older men, with 10.3% of women and 8.4% of men aged 55–64 living in poverty compared with 12.4 and 7.0%, respectively, among those 65 and over.
- *Minority elderly:* Older adults are a highly diverse group, ethnicity and race as well as sexual orientation are important characteristics to consider.

Ethnicity and Race

The status and resources of many ethnic minority seniors reflect social and economic discrimination experienced earlier in life. Many seniors, especially those who immigrated to the US, face cultural and language differences as well. Consequently, ethnic/racial minority groups in the US have increased risks for lower educational levels, substandard housing, poverty, malnutrition, and generally poor health. Health care assistance is a special concern of minority older persons because cultural and language differences, along with physical isolation and lower income, often make US health care services difficult to access. In recent years, the older population has been growing faster among minorities than among whites, and this trend is expected to continue. In 1990, about 4.2 million persons, or 13% of the population 65 and over, were non-White. By 2025, 25% of the elderly population is projected to be non-White.

Sexual Orientation

Lesbian, gay, bisexual, and transgender (LGBT) older adults have been referred to as a “twice hidden” group, that is, a group that is invisible within the mainstream (heterosexual) senior population, regardless of ethnicity or race.

Precise numbers on LGBT older adults are not available because data on sexual orientation are not routinely collected. However, using extrapolations from national surveys, it has been estimated that between 1.4 and 4.3% of women and 2.8 and 9% of men are LGBT. If one applies these ranges to the current estimates on the number of older adults (33 million women and 26.6 million men), there are between 1,206,800 and 3,813,000 LGBT older adults (462,000–1,419,000 women and 744,800–2,394,000 men). Although many of the needs of LGBT seniors are similar to those of other seniors, such as concerns about independence, finances, loneliness, and health, LGBT seniors have needs that are unique to this group. For example, an assumption of heterosexuality by health care providers may result in dissatisfaction with the quality of care (e.g., lack of culturally appropriate care) and substandard medical care (e.g., some screening tests not being recommended as the provider assumes that the partner is of the opposite sex).

- *Family support.* Contrary to popular belief, seniors are not typically abandoned by their families, and admission to a nursing home is usually a last resort. But as the number of frail older persons continues to grow, so does the burden placed on those who care for them.

Social Security

Social Security has been the cornerstone of the nation's income protection system for nearly 70 years. It provides disability, retirement, and life insurance protections to virtually all American workers and their families. As the Western world underwent the industrial revolution, the extended family and the family farm as sources of economic security became less common as more people became wage earners, working for others. Along with the shift from an agricultural to an industrial economy, Americans moved from farms and small rural communities to larger cities. In 1890, only 28% of the US population lived in cities; by 1930, this percentage had doubled to 56%. However, the Great Depression of the 1930s triggered a crisis in the nation's economic life, and it was against this backdrop that the Social Security Act emerged.

Social Security has turned out to be the nation's top antipoverty program. It is particularly important to older women and people of color, who are more likely to face poverty in their retirement years. Social Security's benefit formula is weighted so that lower- and average-wage workers will receive benefits replacing a larger percentage of earnings than higher-wage workers. This means that those who earned less will have a more adequate retirement income than they might have had otherwise. Largely because of Social Security, the poverty rate among older Americans fell from 35% in 1959 to under 11% in 1999, and less than 10% in 2004. Without Social Security, 15 million more Americans would be living in poverty—not only the seniors and the disabled, but almost 1.5 million children as well.

Healthy Aging

Healthy aging is a broad concept that is more than just physical health status or the absence of disease; it encompasses many other important aspects of health, including intellectual, emotional, social, vocational, and spiritual health. If these critical areas are out of balance, optimal healthy aging may be impaired. Behavior and lifestyle choices impact each of these aspects of health; therefore, any program designed to facilitate optimal health in aging must address these areas through education, behavior modification, and supportive environments.

The most current data show that Americans, although living longer, are not necessarily living in better health during their senior years. Since 1990, healthy life expectancy (the number of healthy years after the age of 65) has remained at about 12 years. The good news is that the current gap between life span and healthy life span can be narrowed, and the primary responsibility rests with older adults themselves.

Seventy percent of the physical decline that occurs with aging is related to modifiable factors, including smoking, poor nutrition, lack of physical activity, injuries from falls, and the failure to use Medicare-covered preventative services. Seniors can and should be encouraged to reduce harmful behaviors, such as stopping or

reducing smoking, and increase healthy behaviors, such as exercising and healthy eating. In the area of mental health, primary care physicians, if given the right screening tools, may do a better job of diagnosing and treating depression and other mental disorders among older patients. In addition, providing training and education in geriatrics to practicing physicians, nurses, pharmacists, and other health care professionals can help them better address the health needs of older patients.

According to a 2004 report by The Merck Institute of Aging and Health, the Centers for Disease Control and Prevention (CDC), and the Gerontological Society of America (GSA), Americans are living longer due to declines in heart disease and stroke mortality, but chronic diseases, such as diabetes and high blood pressure, are becoming more prevalent among older adults—especially among African Americans and Hispanics. Among those aged 65–74, the share of those reporting very good to excellent health rose to 42% in 1999, an increase of 7% from 1982. Those aged 75 or older, however, reported little improvement or a decline in health status. Although national goals for improving the health status of older Americans for smoking, colorectal cancer screening, mammograms, and flu vaccinations were met, targets for physical exercise, nutrition, weight, pneumonia vaccinations, and injuries and deaths due to falls, were not.

Good mental health is an important part of healthy aging. Almost 20% of older Americans experience mental disorders. Many primary care physicians are not trained to screen for mental illness, and, unfortunately, may attribute psychiatric symptoms to “normal aging” or to chronic physical illness. As a result, close to 90% of depressed older patients in primary care receive little to no treatment, despite the availability of effective treatments. Only 3% of older adults receive treatment for mental disorders from a mental health specialist. Finally, access to appropriate and quality health care is critical for healthy aging. Yet most health care professionals do not receive the geriatrics training necessary to respond to the unique and complex health needs of older adults. As such, inaccurate diagnoses and inappropriate care often result. Studies indicate that older patients who receive care from geriatric-trained professionals show greater improvement than those treated with usual care. According to one estimate, proper geriatric care could reduce hospital, nursing home, and home care costs by at least 10% a year, saving \$133.7 billion in 2020 (The Merck Institute on Aging and Health, 2004).

Aging Issues

Nutrition

Seniors tend to be at a disproportionate risk of poor nutrition that can adversely affect their health. According to the US Food and Drug Administration (FDA), the signs and symptoms of malnutrition can baffle and mislead even health professionals. For example, weight loss, disorientation, lethargy, and loss of appetite are often diagnosed as illness-related. Unfortunately, encouraging older citizens to eat well and to pay serious attention to sound nutrition is a complex challenge with no single, simple solution. For one thing, the aging process itself becomes a real barrier. As interest in food diminishes, incomes fall, and other health issues affect appetite, seniors may cut back on calories even though the requirements for many nutrients do not change. Other factors that may affect one’s nutritional status are not so obvious. Loneliness, for example, can cripple a person who has always lived with a spouse or other family members. With limited cooking or shopping skills, older men may eat less or skip meals altogether. Women living alone may simply grow tired of preparing food and lose interest in eating. Depression, which is often linked to loneliness, may likewise curtail a person’s interest in food.

Exercise

Lack of physical activity and poor diet contribute to chronic diseases and are the major causes of the obesity epidemic in this country. Despite overwhelming evidence demonstrating the now well-known benefits of physical activity, older adults have the lowest rates of activity among all adults. Nearly 75% of older Americans do not participate in any routine physical activities.

Chronic Diseases

Chronic diseases are not generally prevented by vaccines or cured by medication, nor do they just disappear. To a large degree, the major chronic disease killers—heart disease, cancer, stroke, and diabetes—are an extension of what people do, or not do, as they go about their daily lives. Eighty-eight percent of those over 65 years of age have at least one chronic health condition. Health damaging behaviors, particularly tobacco use, lack of physical activity, and poor eating habits, are major contributors to the nation's leading chronic diseases. Clearly, promoting healthy behavior choices, through education, community policies, and practices, is essential to reducing the burden of chronic diseases.

- *Arthritis* and related conditions are the leading cause of disability in the United States, affecting nearly 43 million Americans. Although cost-effective interventions are available to reduce the burden of arthritis, they are currently underused. Regular, moderate exercise offers a whole host of benefits to people with arthritis by reducing joint pain and stiffness, building strong muscle around the joints, and increasing flexibility and endurance.
- *Cardiovascular health* is a growing concern for all Americans. Heart disease is the nation's leading cause of death. Three health-related behaviors—tobacco use, lack of physical activity, and poor nutrition—contribute markedly to heart disease. Modifying these behaviors is critical for both preventing and controlling heart disease. Modest changes in one or more of these risk factors among the population could have a profound public health impact.
- *Colorectal cancer* is the second leading cause of cancer-related deaths in the United States, accounting for 10% of all cancer deaths. The risk of developing colorectal cancer increases with advancing age. Lack of physical activity, low fruit and vegetable intake, a low diet, obesity, alcohol consumption, and tobacco use may contribute to the risk for colorectal cancer. Three screening tools—flexible sigmoidoscopy, colonoscopy, and the fecal occult blood test (FOBT)—are widely accepted and used to detect colorectal cancer in its earliest stages, when treatment is most effective. However, according to the CDC, in 2000, only 45% of men and 41% of women aged 50 years or older had undergone a sigmoidoscopy or colonoscopy within the previous 10 years or had used an FOBT home test kit within the preceding year.
- *Diabetes* is a serious, costly, and increasingly common chronic disease. Early detection, improved delivery of care, and better self-management are the key strategies for preventing much of the burden of diabetes. Seven million persons aged 65 years or older (20% of all people in this age group) have diabetes.
- *Obesity* has reached epidemic proportions among Americans in all age groups. Obesity among adults has doubled since 1980. Of Americans over the age of 50, 28% are now considered obese. People who are obese or overweight are at increased risk for heart disease, high blood pressure, diabetes, arthritis-related disabilities, and some cancers. After the age of 50, metabolic rates drop sharply; metabolism may drop by 30% over the course of a lifetime. A decreased calorie need must be taken into account when considering elder nutrition: as people age, most simply do not need to eat as much. Although body fat tends to rise with age, muscle mass tends to drop. To maintain muscle mass, higher amounts of protein but fewer calories may be required.
- *Oral health* is an important and often overlooked component of an older adult's general health and well-being. Oral health problems, such as ill-fitting dentures, poor condition of the teeth and gums, or side effects from medications, can cause pain and suffering as well as difficulty in speaking, chewing, swallowing, and maintaining a nutritious diet. During the past 50 years, the oral health and use of dental services among older adults have improved. Although this trend is expected to continue, additional improvement will depend on access to appropriate dental care.

Mental Health

As a person ages, signs of depression are much more likely to be dismissed as crankiness or grumpiness. Confusion or attention problems caused by depression can sometimes look like Alzheimer's disease or other

brain disorders. Mood changes and signs of depression can be caused by medicines older people may take for high blood pressure or heart disease. An estimated 2 million adults aged 65 or older have a depressive illness, and another 5 million may have “subsyndromal depression” or depressive symptoms that fall short of meeting full diagnostic criteria for a disorder. Subsyndromal depression is especially common among older persons and is associated with an increased risk of developing major depression. In any of these forms, however, depressive symptoms are not a normal part of aging. In contrast to the normal emotional experiences of sadness, grief, loss, or passing mood states, they tend to be persistent and to interfere significantly with an individual’s ability to function.

Depression often co-occurs with other serious illnesses, and because many older adults face these illnesses as well as various social and economic difficulties, health care professionals may mistakenly conclude that depression is a normal consequence of these problems—an attitude often shared by patients themselves. These factors together contribute to the underdiagnosis and undertreatment of depressive disorders in older people. Depression can and should be treated when it co-occurs with other illnesses because untreated depression can delay recovery from or worsen the outcome of these other illnesses. The relationship between depression and other illness processes in older adults is a focus of ongoing research.

Suicide

Several studies have found that many older adults who die by suicide—up to 75%—have visited a primary-care physician within a month of their suicide. These findings point to the urgency of improving detection and treatment of depression as a means of reducing suicide risk among older persons. Comprising only 13% of the US population, individuals aged 65 and older accounted for 18% of all suicide deaths in 2000.

Alzheimer’s and Related Dementias

Alzheimer’s disease is a complex disease of the brain that affects approximately 4.5 million Americans. Although many things about Alzheimer’s disease remain a mystery, research continues to bring us a better understanding of the disease, more accurate diagnoses, and more effective treatments. Alzheimer’s disease is one of several disorders that cause the gradual loss of brain cells. One in 10 persons over 65 and nearly half of those over 85 have Alzheimer’s. A very small percentage of people as young as their thirties and forties will also get the disease. A person with Alzheimer’s disease will live an average of 8 years from the onset of symptoms. More than 70% of people with Alzheimer’s disease live at home and almost 75% of the home care is provided by family and friends, creating a great need for caregiver support and training.

Dementia is an umbrella term for several symptoms related to a decline in cognitive functions. Common symptoms include a gradual loss of memory, problems with reasoning or judgment, disorientation, difficulty in learning, loss of language skills, and decline in the ability to perform routine tasks. People with dementia also experience changes in their personalities and behavioral problems, such as agitation, anxiety, delusions (believing in a reality that does not exist), and hallucinations (seeing things that do not exist).

Several disorders that are similar to Alzheimer’s disease can cause dementia. These include frontotemporal dementia, dementia with Lewy bodies, Parkinson’s disease, Creutzfeldt–Jakob disease, and Huntington’s disease. All of these disorders involve disease processes that destroy brain cells. Vascular dementia is a disorder caused by the disruption of blood flow to the brain. This may be the result of a massive stroke or several tiny strokes. Some treatable conditions—such as depression, drug interactions, and thyroid problems—can also cause dementia. If treated early enough, this type of dementia may be effectively treated and even reversed.

Substance Abuse

It is estimated that one in five older people abuse substances. Although the substances most abused, for example, prescription medications and alcohol, are legal, this does not make the addiction any less devastating for them and

their families. Substance abuse by seniors can lead to depression, dramatic personality changes, memory loss, malnutrition, falls, several forms of cancer, heart disease, and early death.

Health, Health Care, and Disability

According to a report issued by AARP in 2000, 27% of older adults assessed their health as fair or poor (as compared to 9% for all persons). There was little difference between the sexes on this measure, but older African Americans (41.6%) and older Hispanics (35.1%) were much more likely to rate their health as fair or poor than were older Whites (26%).

Limitations on activities because of chronic conditions increase with age. In 2000, among those 65–74 years old, 26% reported a limitation caused by a chronic condition. In contrast, almost half (45%) of those 75 years and over reported they were limited by chronic conditions. The percentage of seniors with disabilities increases sharply with age. Disability takes a much heavier toll on the very old. Almost three-fourths (74%) of those aged 80 and older reported at least one disability. Over half (58%) of those aged 80 and over had one or more severe disabilities, and 35% of those 80 and over reported needing assistance as a result of disability. There is a strong relationship between disability status and reported health status. Among those aged 65 and older with a severe disability, 68% reported their health as fair or poor. Among persons aged 65 and older who reported no disability, only 11% reported their health as fair or poor. Presence of a severe disability is also associated with lower income levels and educational attainment.

Immunizations for Older Adults

Although infectious diseases are no longer the most common causes of death, pneumonia and influenza remain among the top ten causes of death for older adults. In 2000, pneumonia and influenza were responsible for 3.3% or 58,557 deaths among people 65 years of age and older. Influenza vaccination can reduce both direct health care costs such as physician visits and antibiotic use, as well as indirect costs from work absenteeism associated with influenza illness.

Legal and End-of-Life Decisions

Although many people would prefer not to think about the end of their lives, planning increases the chances that one's wishes will be met. In addition to preparing a will, estate planning should include preparing and signing advance directives that comply with state law. The documents should reflect the senior's wishes and appoint someone to make decisions for him/her if he/she is unable to do so. Advance directives include either or both of these documents:

- *Living Will or Health care Directive.* This document allows one to state in advance one's wishes regarding treatments that may prolong life.
- *Health care Power of Attorney or Durable Power of Attorney for Health care Decisions.* This document allows one to name a person to make health care decisions for him/her.

Housing

Housing plays a unique role in the life of older Americans. In addition to serving as shelter, it provides a sense of comfort and security. It also provides wealth to approximately 80% of Americans aged 50 and older who own their own homes. Safe and secure housing can influence the ability of an older person to age in place and remain independent. Yet many older people experience serious housing problems because of cost, inappropriateness of

the home for aging in place, or challenges to protecting their financial interest in the home. In addition, enjoying the benefits of home and community may be difficult without improved home and community services programs and legal protections.

The 1999 American Housing Survey indicated that 55% of renter households aged 65 and older incurred “excessive expenditures,” defined as housing costs in excess of 30% of income. The percentage of older households with excessive housing expenditures was particularly high for subgroups such as renter households headed by individuals aged 75 and older (59%), females living alone (60%), and older African Americans (63%).

For older homeowners, the home is usually their single largest asset. Older persons can use this wealth for a variety of purposes: to serve as collateral for the upgrade and repair of the property, to provide economic security in the face of major unforeseen expenses (such as long-term care), and to provide shelter or finances to future generations through inheritance. Home ownership is growing: between 1982 and 2001, the home ownership rate for households aged 65 and older grew from 74 to 80%. Home repair programs and improved construction standards for manufactured homes can help safeguard this physical asset. Standards for reverse mortgages and other financial instruments can provide reliable options for using the equity in a home.

The physical features of housing can be critical to a person’s ability to age in place. Much of the nation’s current housing may prove inappropriate as the population ages, especially for those people experiencing increased frailty. Home modification is one method to help meet the changing needs of an aging resident. There is also growing recognition that promoting adaptable and accessible design into homes as they are built may generate significant financial and social benefits down the road. But regardless of a home’s features, many older people, especially those who live alone, eventually need some supportive services to remain independent.

The growing population of people aged 75 and older will present special challenges. Households headed by an individual aged 75 or older are more likely than those headed by 65–74-year-olds to be renters, live alone, and experience poverty, health problems, and substandard housing conditions. Meeting these multiple needs will require housing subsidies, more extensive provision of in-home health care, and community support services, such as transportation.

The “oldest-old” who can no longer stay in their homes will require specialized housing with more extensive services such as assisted living, congregate housing, or group homes. Unfortunately, many older people with moderate or low incomes cannot afford such specialized supportive housing on their own, and current state subsidy programs are limited. One crucial challenge for policy makers will be determining how to extend supportive housing opportunities to frail older people with modest means. The problem is especially acute for older renters, who not only have fewer financial resources, but also are more likely to live alone and have difficulty with everyday activities.

Transportation

Automobiles

For many seniors, transportation is a critical concern. The majority of seniors see driving as crucial to being able to lead an independent and fulfilling life. Fears faced by seniors at the prospect of reducing or terminating their driving include loss of personal independence, social isolation, and a reduction in or lack of access to essential services. The point at which older people voluntarily give up or are forced to relinquish their driving privileges is viewed by elders and those around them as a watershed event with significant implications regarding independence, self-sufficiency, and social responsibilities.

The tendency of seniors to rely on personal autos as their primary means of transportation is increasing. Driving rates among people 60 years of age and older are increasing, and people are continuing to drive later in life. The increases are most dramatic for women, who used to have much lower licensing rates than men. As today’s near-seniors age, with their high rates of driving, the percentage of older women who drive will continue to increase. Most older adults believe that they will know when they should stop driving, yet most have peers whose driving they consider to be so unsafe that they will not accept rides from them. When faced with the

difficult transition from driving to not driving, most families struggle alone. Studies have reported that most families have never discussed driving issues with anyone, and most do not know where to obtain information or advice. There is widespread interest in and need for such resources. Owning an auto is expensive, especially if someone seldom drives or drives only short distances (as do many seniors), yet few seniors understand how much mobility they could purchase for their car's annual cost.

Public Transit

Ability to use public transit also declines with age. Based on national survey data, 7% of people aged 69–74 are prevented or limited from using public transit by an impairment or health problem. For the 85 and older group, this percentage rises to 35%. In the case of seniors who can no longer drive due to an impairment or health condition, fully 55% are also limited or prevented from using public transit. Since the number of seniors, especially in the oldest age group, will grow rapidly, and since so many of those people cannot use public transit, there will also be a rapid increase in the number of people who are eligible for “paratransit” services, as required by the Americans with Disabilities Act (ADA). Paratransit services are defined as transport services, usually vans and small buses, for people with disabilities who cannot use existing fixed-route bus and train services. Federal law and increasing mobility by people with disabilities, in general, will probably cause even greater growth in paratransit use.

As people age, they face unique challenges in getting around in their communities. Helping older adults maintain this essential mobility is a major concern of transportation planners throughout the country. Not only is the size of the senior population expected to grow rapidly, the most rapid growth is expected to occur in the oldest age groups, which have the most severe mobility problems. Further, much of the growth will occur in places that are poorly served by public transportation. Even in places where transit service is good, many seniors do not use it because they have little familiarity with the transit system and are used to relying on personal automobiles as the most convenient mode of travel.

Grandparents Raising Grandchildren

Grandparents raising their grandchildren are responding to a problem in the middle (parent) generation, such as death of the parent, illness, divorce, incarceration of the parent, parental substance abuse, child abuse, or child neglect. For example:

- There are 4.5 million children under 18 years growing up in grandparent-headed households, and approximately one-third of these children have no parent present in the home.
- The number of children in grandparent-headed households has increased by 30% since 1990.
- The majority of grandparents raising grandchildren are between ages 55 and 64 and approximately 20–25% are over 65.
- Fifty-one percent of grandparents raising grandchildren are White, 38% African American, and 18% Hispanic.
- Although grandparent-headed families cross all socioeconomic levels, grandparents raising their grandchildren are more likely to live in poverty than other non-grandparent-headed households.
- There are eight times more children in grandparent-headed homes than in the foster care system.

Grandparents are faced with many challenges. They must investigate and resolve legal questions around custody, guardianship, or adoption. Without legal status, grandparents may not be able to enroll their grandchildren in schools or make medical decisions for them. Grandparents are forced to make financial decisions that may involve the grandparent's employment or applying for benefits like Medicaid, foster care, temporary assistance for needy families (TANF), or Social Security. Grandparents are faced with choosing appropriate child care, providing adequate medical care, educating and providing emotional support to their grandchildren, and finding support for themselves.

Elder Abuse

Elder abuse is an unspoken horror in the lives of many older persons. Four to six percent of America's senior population may be victims of some form of abuse, accounting for 2.4–3.6 million potential victims every year. Elder abuse is a largely unreported crime that will only get worse as 77 million baby boomers reach age 65 over the next decade. Older adults who are abused or mistreated are three times more likely to die within a decade than same-age adults who were not mistreated. Persons from all social classes and ethnicities are the victims of abuse.

Many of these abusers are criminals who prey on the elderly, but the majority are caregivers or relatives pushed to the brink of violence and neglect from daily stress combined with oftentimes overwhelming responsibilities. Forty percent of all elder abuse involves some form of financial exploitation. This is of increasing concern because nearly 70% of our nation's household net worth is controlled by people over the age of 50. Perpetrators abuse older persons for a variety of reasons, but the main causes have to do primarily with dependency and vulnerability. If an abuser is the primary caregiver and the caregiver views the dependency of an older adult as burdensome and stress producing, the caregiver may exhibit abusive behavior. If the abuser is not the caregiver, the dependency of an older adult creates vulnerability to persons who seek to exploit dependence. Finally, if an abuser simply does not know how to care for an older adult, abuse may occur through passive neglect.

Fiduciary Abuse

In a survey by the National Association of Adult Protective Services Administrators for the National Center on Elder Abuse (2000), financial abuse or exploitation comprised 13% of the allegations of mistreatment that were investigated. Although people over age 65 represent 12% of the population, experts estimate that, more than 30% of consumer fraud investigations involve people in this age group. Fiduciary abuse, exploitation, and financial mistreatment encompass a broad range of conduct. Examples include the attendant who shortchanges his/her elderly client, the neighbor who secures a power of attorney to help out with chores and uses it to take possession of an older person's home, and the son or daughter who persuades an impaired elderly family member to change a will in his/her favor.

Of all the types of elder abuse, financial abuse may be the most difficult to grasp because the problem itself is poorly defined. Evaluating whether or not financial abuse has occurred often involves complex and subjective determinations. It may involve differentiating between misconduct and mismanagement, or distinguishing between acceptable exchange and exploitative conduct. Abuse may be obscured by the victims' diminished mental capacity, which makes it unclear as to whether or not they understood the transactions or exchanges. Even when victims are mentally competent, it may be unclear as to whether or not they were the victims of unfair persuasion.

Many reasons have been cited for why the elderly are targeted for financial abuse. Clearly, one contributing factor is that persons over the age of 50 control 70% of the nation's wealth. Other explanations include the fact that older people are more trusting than their younger counterparts, they may not realize the value of their assets, and the perpetrator may be someone they trust and love. Additionally, they are more likely to have conditions or disabilities that make them easy targets including forgetfulness or other cognitive impairments. They are also less likely to take action against their abusers, particularly if they have been victimized by family members. Abusers may also recognize that older people who are in extremely poor health may not survive long enough to follow through on lengthy legal interventions.

Crime

Although adults aged 65 or older experienced less violence and fewer property crimes than younger persons between 1992 and 1997, crime committed against seniors is still a serious problem. According to the Bureau of Justice, persons aged 65 or older, when compared with other age groups, are disproportionately affected by property crimes. For example, nine out of ten crimes against individuals aged 65 or older were property crimes,

whereas less than four of ten crimes against individuals 12–24 years were property crimes. Between 1992 and 1997, an average of 2.5 million property crimes against persons aged 65 or older occurred annually. However, during the same time period there was an annual average of 46,000 purse snatchings or pocket pickings, 166,000 nonlethal violent crimes (rape, sexual assault, robbery, and aggravated and simple assault), and 1000 murders committed against older adults. Robbery accounted for a quarter of the violent crimes against persons aged 65 or older, which is less than one-eighth of the violent crimes experienced by those aged 12–64.

Violence Against Midlife and Older Women

Although the statistics on this issue are sparse, anyone who interacts with older women knows that violence and fear of violence pervade their lives. Facts on violence against midlife (50–64 years) and older (65+ years) women include the following:

- Twice as many women over the age of 65 are mugged at or near their homes as younger women, and are much more likely to have the incident occur during daylight. In fact, three of four muggings involving women aged 65 and over occur during daylight.
- One of every hundred women aged 50–64 is likely to be a victim of a violent crime (including assault, rape, and robbery), and two of every hundred women aged 65 or older are likely to be a victim of personal larceny (theft of property or cash with and without contact).
- Midlife and older African American women are more than twice as likely as White women in the same age groups to be victims of violent crimes.
- Between 1974 and 1990, the murder rate for women aged 65 and older increased by 30%, whereas the murder rate for men for the same age dropped by 6%.
- According to a national survey of the health of women conducted for the Commonwealth Fund in 1992, an estimated 1.4 million women between the ages of 45 and 64 were physically abused by their spouses.
- Of more than 1500 shelters for battered women nationwide, few offer programs specifically designed to meet the needs of older battered women. For instance, a study of 25 shelters in Florida—where there are a disproportionate number of older people—found that just two offered services for older women.
- More than a million American women aged 65 and over are victims of abuse each year.
- Nearly 400,000 older women living in institutions are victims of physical or sexual abuse. In one study, more than 36% of care providers in institutional facilities had witnessed at least one incident of physical abuse by another staff person, and four in five (81%) had witnessed an incident of psychological abuse (House Select Committee on Aging, 1991).
- In elder sexual abuse cases, the victim is typically a woman in her seventies, dependent for care upon the person who abused her.

Conclusions

As the United States faces a rapidly increasing population over the age of 65, research on what constitutes healthy aging, how to promote healthy lifestyles among older adults, and the health care workforce, including professional and paraprofessional, requirements is urgently needed. Older adults, and in particular seniors, have not traditionally been viewed as a productive segment of the population. However, with more seniors in the public arena either through employment or volunteer work, perceptions of people over the age of 65 are slowly changing, and hopefully becoming more positive. Older adults themselves have not always viewed the aging process as a positive process; hence, healthy aging can serve as a framework within which health promotion messages and prevention services can be offered. The increasing senior population is also increasingly diverse across many demographic variables, including ethnicity and race, sexual orientation, religion, and language, among others. The challenges to creating a diverse health care workforce, in general, are significant, that of ensuring diversity in the health and social services targeting the older population is even greater.

Related Topics

▶ Access to health care, ▶ Advance directives, ▶ Alzheimer's disease, ▶ Cancer, ▶ Coronary risk factors, ▶ Crime, ▶ Dementia, ▶ Depression, ▶ Diabetes, ▶ Durable power of attorney for health care, ▶ Elder abuse and neglect, ▶ Ethnicity, ▶ Exercise, ▶ Grandparents as parents, ▶ Housing, ▶ Immunizations, ▶ Institutionalization, ▶ Loneliness, ▶ Long-term care, ▶ Mental illness, ▶ Minority seniors, ▶ Nursing home, ▶ Nutrition, ▶ Obesity, ▶ Oral health, ▶ Osteoarthritis, ▶ Race, ▶ Social Security, ▶ Substance use, ▶ Suicide, ▶ Transportation services, ▶ Violence.

Suggested Readings

Hoffman C, Rice D (1996) Chronic care in America: A 21st century challenge prepared by the Institute for Health and Aging, University of California, San Francisco, for The Robert Wood Johnson Foundation. RWJF, Princeton, NJ.

United States Department of Health and Human Services (1991) Healthy people 2000: national health promotion and disease

prevention objectives. Public Health Service Publication #017-001-00473-1. U.S. Government Printing Office, Washington, DC

Zians J (2004) The San Diego County LGBT Senior Healthcare Needs Assessment. LGBT Seniors—Proud Pioneers. Alliance Healthcare Foundation, San Diego, CA. www.alliancehf.org

Suggested Resources

American Association of Retired Persons (1995–2005). <http://www.aarp.org>

Merck Institute on Aging and Health (2004) The state of aging and health in America 2004 (2005). http://www.miahonline.org/press/content/11.22.04_SOA_Report.pdf

National Institute on Aging (1998) Baltimore Longitudinal Study of Aging: 1958–1998. Selected findings from 1978 to 1998. National Institutes of Health, Bethesda, MD. <http://www.grc.nia.nih.gov/branches/blsa/blsnew.htm> (September 1, 2005)

National Institute of Aging and the National Library of Medicine. NIH Senior Health National Institutes of Health, Bethesda, MD.

<http://nihseniorhealth.gov> (October 24, 2005)

United States Census Bureau. Your gateway to Census 2000. Washington, DC. <http://www.census.gov>

United States Department of Health and Human Services. Healthy people 2010: a systematic approach to health improvement. Office of Disease Prevention and Health Promotion, Rockville, MD. <http://www.healthypeople.gov>

3 Cultural Diversity among Elders in the US: Meeting the Challenge of the Ethnogeriatric Imperative

Gwen Yeo

America's Ethnogeriatric Imperative

Demographers, teachers, and reporters have made the vision of the bulge in the population pyramid that is approaching the age of Social Security and Medicare benefits familiar to the American public and the public health community. Its predicted influence on health care is frequently referred to as “the geriatric imperative.” Not so familiar, however, is the recognition that this bulge of older Americans represents an increasingly diverse population—diverse in many ways, but especially in their ethnic background, so that, in reality, *the imperative is an ethnogeriatric one*.

The ethnic population categories for which data are available are those used by the census and other federal agencies, designated as the “ethnic minority” populations. The projected growth of the number of elders from those categories from 2000 to 2050 is included in [Table 1](#). The categories considered “races” by the US Census are American Indian and Alaska Native, Asian, Pacific Islander, black or African American, and white; Hispanics or Latinos can be of any “race,” as defined by the census, so that the separation by Hispanic and non-Hispanic is necessary for each racial group. Projections are that more than one in three of the projected 80 million elders will be from one of the “ethnic minority” categories by mid-century and that all are growing more rapidly than non-Hispanic whites (Federal Interagency Forum on Aging Related Statistics 2000).

Although the projections for the growth of elders in these populations are impressive, it drastically underrepresents the diversity the US will increasingly experience. Within each of these populations designated as ethnic minority is a vast heterogeneity. Among the rapidly growing set of elders in the Hispanic/Latino designation, for instance, the most numerous are those who describe themselves as Mexican, and smaller proportions from Puerto Rico and Cuba. But in addition, Hispanic/Latino elders are from seven different countries in Central America, ten in South America, and from Spain.

Soon to be the second largest minority population are elders who describe themselves as black or African American. While US-born African American elders make up the vast majority, immigrants from the Caribbean and from Somalia, Nigeria, and other African nations are also part of this category and will make up a growing proportion as they age. As is true in all of the population categories, large and important differences exist among African American elders in education, rural/urban background, income, occupation, religion, family support, living arrangements, health and functional status, and almost all other variables that affect public health concerns.

It is particularly important to recognize the heterogeneity among older Asian and Pacific Islander Americans as their cultural traditions originate in countries that span more than half the globe, and frequently have very little in common with each other, in spite of the common usage of term “Asian” to designate individuals in this category. [Table 2](#) illustrates some of the heterogeneity of these populations.

The unique and frequently unrecognized differences also apply to elders from American Indian background. There are over 500 federally recognized tribes in the US, and many smaller groupings known as bands or *rancherías*, most of whom have their own specific histories and cultures. More American Indian elders than those from other racial categories described themselves as being from more than one race when they had that opportunity in the 2000 census, which emphasizes the diversity in acculturation among this group. Another important source of diversity is the difference in types of communities in which they live. In spite of the stereotype

■ Table 1

Relative size of older ethnic minority populations in the US 2000 & 2005

Ethnic minority category	Percent of US population	Projected percent of US population
	65 and Over, 2000	65 and Over, 2005
Hispanic or Latino	6	16
Non-Hispanic American Indian and Alaska Native	0.4	0.6
Non-Hispanic Asian and Pacific Islander	2	7
Non-Hispanic Black or African American	8	12
Non-Hispanic White	84	64

Source: From Federal Interagency Forum on Aging Related Statistics (2000)

of Indians on remote reservations, more Indian elders are now in urban areas than on reservations, which means that they have less access to Indian Health System resources.

Elders in the “white” non-minority population are also very ethnically diverse. In addition to those from Northern and Western European backgrounds usually associated with the white designation, increasing numbers of elders in the US are from Arab and other countries in the Middle East. Older immigrants from Russia and other Eastern European countries also comprise populations with unique cultural backgrounds and needs.

Celebrate the Diversity and Appreciate the Complexity

This ethnogeriatric imperative presents providers who work with older adults an amazingly diverse population with which to be familiar, if they are to provide competent care, and that diversity provides interest, fascination, and richness, which is to be celebrated. It also presents amazing complexity that needs to be appreciated in itself. However, if one also considers the increasing ethnic diversity of the providers working with older Americans, that complexity multiplies many times over. This is especially evident in long-term care settings where individuals from countries around the globe have taken positions on the nursing staff in nursing homes and in assisted living communities in the US. This is also true in geriatric medicine where the ethnic background of geriatric fellows reflects an international population, many of whom go on to take positions in geriatric medicine in hospitals and clinics. As a result of the growing diversity of both the elders and their providers, the probability that a clinical encounter will be an intercultural interaction becomes very high.

So what difference does all this complexity make? At a minimum, it means that the need for cultural competence in geriatric care is probably the most important need for organizations to develop in meeting the challenge of this ethnogeriatric imperative. With the increasing attention to the disparities in health status and health care between ethnic populations highlighted in the publication of the Institute of Medicine (2002) report, “*Unequal treatment: confronting racial and ethnic disparities in health care*,” and among older Americans (Anderson et al. 2004; Schneider et al. 2002), cultural competence has become a suggested tool to decrease those disparities (Brach and Fraser 2000).

Organizational Cultural Competence

The term “cultural competence” is becoming increasingly common, and organizations are encouraged to use it as a guidepost for their missions and goals. There are numerous definitions in the literature, but most include some of the components proposed by Cross et al. (1989) in one of their earlier papers: “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or amongst professionals, and enables that system, agency, or those professionals to work effectively in cross-cultural situations.”

The two parts of cultural competence commonly identified are organizational or institutional and provider competence. The organizational component is usually conceptualized as a continuum. Although there are other versions of this continuum, the one suggested by the pioneering work of Cross et al. (1989) indicates that

Table 2
Asian and Pacific Islander American elders 65 and over, 2000

Ethnic identification	Number 55+	Number 65+	Percent of Asian 65+	Percent 65+ foreign-born ^a	Percent 65+ in poverty	Percent 65+ with education		Percent 65+ linguistically isolated ^b
						<9 years	Bachelor's +	
Asian American alone	1,577,339	800,795	100	NA	12.3	30.9	20.8	30
Chinese	418,300	235,995	29.5	84.2	16.2	38.0	21.7	46
Filipino	334,022	164,768	20.6	90.5	8.4	29.4	26.6	17
Japanese	240,527	161,288	20.1	20.0	5.6	11.3	15.2	19
Korean	162,050	68,505	8.6	90.2	22.1	31.7	20.9	53
Asian Indian	176,793	66,834	8.3	88.9	9.1	31.6	31.9	12
Vietnamese	137,729	58,241	7.3	92.1	16.0	47.3	8.4	46
Cambodian	14,975	6,570	0.8	100.0	22.3	73.7	4.6	54
Pakistani	12,174	4,804	0.6	96.7	13.0	30.7	29.8	NA
Hmong	9,056	4,698	0.6	92.61	29.3	91.6	2.0	59
Thai	13,198	2,954	0.4	97.2	11.7	36.2	21.4	31
Other Asian	58,515	26,138	3.2	88.1	8.6	27.2	24.3	NA
Asian in combination with one or more other races	122,860	60,930						
Native Hawaiian and other Pacific Islander (NHPI)	44,391	20,821	100	NA	11.5	24.6	9.4	NA
American alone								
Native Hawaiian	21,581	10,451	50.2	NA	9.3	18.8	9.1	NA
Samoa	7,721	3,567	17.1	NA	16.5	32.4	7.9	NA
Guamanian or Chamorro	6,090	2,845	13.7	NA	10.9	25.0	13.1	NA
Tongan	2,418	1,030	4.9	NA	12.8	36.3	2.6	NA
Other Pacific Islander	6,581	2,928	14.1	NA	NA	NA	NA	NA
Native Hawaiian and other Pacific Islanders in combination with one or more races	90,793	43,802			12.5	23.2	11.5	NA

NA, not available

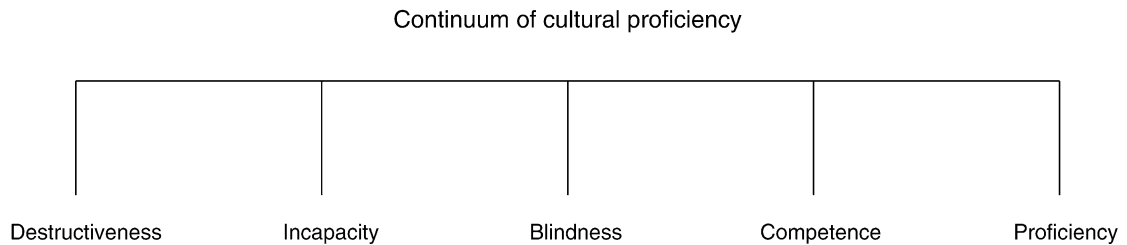
^bData on linguistically isolated are from 1990 since they were not available from the 2000 census; it should be noted that some of the data are from very small samples so they may not be completely accurate

Source: From 2000 Census Data provided to author by A. Locsin, National Asian Pacific Center on Aging, Seattle

■ **Figure 1**

Continuum of cultural proficiency

Source: From Cross et al. (1989).



organizations can be placed on a scale from “destructiveness” to “proficiency” depending on how culturally competent they are, as illustrated in [▶ Figure 1](#). If the two poles of the continuum are thought of as being the extremes, very few organizations are likely to be at either end, especially those serving older adults. Providers in workshops conducted by the Stanford Geriatric Education Center (SGEC) have suggested that perhaps the Ku Klux Klan would be an example of a “destructive” organization, and the United Nations one that fits the requirements of “proficiency.” In reality, most health care organizations would probably lie somewhere between “incapacity” and “competence.” It is interesting to note that “blindness” is placed on the middle of the continuum when many organizations pride themselves as being “color blind,” treating everyone the same. So, the goal for organizations would be to find strategies to move themselves up this continuum toward cultural competence, or even the ideal of proficiency.

One of the motivations that health care organizations have been given to move up the continuum, including outlining techniques that should be used, is the development and publication of the *Standards for culturally and linguistically appropriate services* (CLAS Standards) by the US Office of Minority Health (2000) included in [▶ Table 3](#). These are increasingly being used as guidelines for accrediting agencies for clinical care. Standards 4–7 dealing with language access for patients are actually part of the mandates from the Civil Rights Acts. The remaining standards are highly recommended, except for the last one, which is optional.

The CLAS Standards provide major strategies for organizations to focus on to improve their ethnogeriatric care. Among the most important they call for are:

- a. Training staff to show culturally appropriate respect and to recognize and respect culturally based health beliefs.
- b. Providing trained and competent interpreter services for verbal interactions and translation services for written materials, including posting signs in languages appropriate for the patients in the populations they serve.
- c. Collaborating with diverse communities to assess needs and provide appropriate services for elders from those populations.

Having appropriate interpreter services for all their older non-English-speaking patients is a major challenge for many health care organizations, but is extremely important, especially for elders who may want to talk to their providers about issues not culturally appropriate for family members acting as interpreters to hear, such as gynecological issues or elder abuse. A practice that can be devastating emotionally for children is asking them to act as interpreters for older members of their families because they are not likely to know the terminology involved in English or their native language. If organizations cannot have trained interpreters available for all the major language groups they serve, they are encouraged to make telephone-based services available to their providers.

In addition to the strategies for increasing cultural competence included in the CLAS standards, some other important ones are the following:

- a. Recruiting board members and administrators from the diverse populations they serve so that individuals in policymaking and decision making roles will more likely understand the needs of elders from diverse communities.
- b. Hiring staff at all levels that mirror the population they serve. Level of comfort of new patients is enhanced if they can see someone that “looks like them” or at least might seem to be from a familiar background.

■ **Table 3**

Standards for culturally and linguistically appropriate services, Office of Minority Health, US Department of Health and Human Services

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.
Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.
Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.
Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language-assistance services.
Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff; family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.
Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.
Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.
Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.
Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.
Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.
Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.
Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS Standards and to provide public notice in their communities about the availability of this information.

For more information, see www.omhrc.gov/CLAS

- c. If hiring qualified staff from target populations is not possible, organizations can recruit “cultural guides” or “cultural brokers” from diverse communities to be consultants for appropriate services. They might be from ethnically based religious or civic groups, clan leaders, or interpreters. These resources are especially important to have available when there is a culturally based misunderstanding.

Provider Cultural Competence

The second necessary part of cultural competence is that of individual providers. This can be seen as having three components: attitudes, knowledge, and skills.

Attitudes

Providers' attitudes toward individuals from other cultures or traditions are likely to be the most important but frequently the least accessible part of provider cultural competence. The images and assumptions people have about elders and families from other groups are frequently learned early and emotionally rather than rationally, so that they are more difficult to unlearn directly. The importance of attitudes in clinical care was illustrated by the study of physician referral patterns by Schulman et al. (1999) in which internists and family physicians were half as likely to refer older black women to cardiac catheterization as they were white women and men, and black men with the same symptoms, based on professionally acted video-taped scenarios. The authors concluded that the results suggest bias among the physicians that could be overt prejudice, but was more likely to be based on subconscious perceptions.

To minimize the possibility of similar subconscious perceptions affecting clinical interactions, providers are encouraged to explore their own memories of learning about other groups at an early age, how and what they learned and from whom, so that they can be aware of, and perhaps avoid, potential unintended consequences.

Other strategies to help reduce the effects of unconscious stereotypical images would be for providers to expect within group differences, consciously making note of a wide variety of characteristics they observe in elders and family members from the same ethnic background. For example, if one is clearly aware of both well and poorly educated individuals, those practicing different religions, with different language abilities, and different health beliefs in the same ethnic group, it is more difficult to let specific preconceptions influence decisions and interactions.

Knowledge

There might be a long list of types of information one could make that would be helpful for providers, administrators, and policy makers to know to increase their cultural competence, but given the complexity of the diversity with which health care must deal, reality suggests that there are limits to what can be expected. One valuable guide, *Doorway thoughts: cross-cultural care for older adults*, was developed by the Ethnogeriatrics Committee of the American Geriatrics Committee (Adler and Kamel 2004). Some crucial pieces of knowledge were recommended by Lavizzo-Mourey and MacKenzie (1996) in an early paper on the topic, when they suggested that health care providers should know the specific health risks faced by different populations with which they deal, and their culturally related health beliefs and practices.

Health Risks of Elders from Diverse Backgrounds

Morbidity and mortality data for older Americans are much easier to access for some ethnic populations than others. The majority of the national data sets compare white and black or African American health status; recently, much more is available for elders in the Hispanic category, but little is specific to the Hispanic/Latino subpopulations. The smaller populations frequently have too few individuals in national samples to analyze, so that available data rely on community-based studies. Much of the data for older American Indians come from the Indian Health Service, which includes only those on or near reservations. Given those reservations, examples of available information on differences in health risks are included in [Table 4](#). For a comprehensive review of disparities data on mortality and their limitations, see Hummer et al. (2004).

One particular anomaly should be pointed out in the information available for Hispanic/Latino elders, which is known as the "Latino Paradox." Although much of the morbidity and functional status data indicate greater impairment for Hispanic/Latinos than for non-Hispanic/Latino whites, their death rates are lower. The reason for this paradox is not clear, but possible explanations include misclassification of ethnicity on death records and older immigrants returning to Mexico and other native countries to die.

Health Beliefs and Practices

There are major between-group and within-group variations in the kind and degree of beliefs about health that elders hold. Because these beliefs influence elders' health-seeking behavior, the degree to which they act on clinical recommendations, their satisfaction with care, and their concurrent use of non-biomedical alternative therapies and medications, it is important for providers to be familiar with the major culturally based belief systems they may encounter. Examples of these systems that are very different from the Western biomedical model are: the balance system of health and illness (*yin/yang*) and the influence of the life force *Qi* from classical Chinese medicine, which has influenced many other Asian countries, such as Korea, Japan, and Vietnam; *Ayurvedic* medicine from India that also relies on balance of elements; religiously based beliefs concerning punishment for bad deeds in this life or past lives such as those in Latin America or belief in the *karma* associated with Buddhism; and the influence of spirits in the health beliefs of the Hmong. A more complete description of these and other beliefs are included in the various modules of the online Curriculum in Ethnogeriatrics developed by the inter-Geriatric Education Center Collaborative on Ethnogeriatric Education, which can be accessed at www.stanford.edu/group/ethnoger (Yeo 2001).

■ Table 4

Examples of differences in health risks among ethnically diverse elders in the US

Population	Conditions for which they may be at greater than average risk ^a	Conditions for which they may be at less than average risk ^a
African Americans	Heart diseases	Respiratory diseases
	Cancer (especially prostate)	Osteoporosis/hip fracture
	Cerebrovascular disease/stroke	
	Diabetes	
	Nephritis/kidney disease	
	Septicemia	
	Hypertension	
American Indian	Dementia (especially vascular)	
	Diabetes	Heart diseases
	Cervical, esophageal, and gallbladder cancer	Cerebrovascular disease/stroke
	Cataracts	Respiratory diseases
	Kidney disease	
	Liver disease	
	Tuberculosis	
Asian American	Accidents	
	Hearing problems	
	Adenocarcinoma	Heart diseases
Asian Indian		Cerebrovascular disease/stroke
		Respiratory diseases
Chinese	Diabetes	
	Esophageal, liver, pancreatic, and nasopharyngeal cancer	Breast and colon cancer
	Diabetes	Hypertension
	Vascular dementia	
Filipino	Suicide	
	Hypertension	Cancer
	Diabetes	
	Gout	
Japanese	Tuberculosis	
	Esophageal, liver, and stomach cancer	Breast cancer
		Prostate cancer
	Hemorrhagic stroke	
	Vascular dementia	
	Diabetes	

■ **Table 4 (continued)**

Population	Conditions for which they may be at greater than average risk ^a	Conditions for which they may be at less than average risk ^a
	Osteoporosis	
	Suicide	
Korean	Liver cancer	
Southeast Asian	Depression	
	Posttraumatic stress disease	
Vietnamese	Cervical cancer	
Pacific Islander (Guamanian)	Hypertension	
	Diabetes	
	Obesity	
	Parkinson's disease	
Hispanic/Latino	Adenocarcinoma	Respiratory diseases
		Accidents
Mexican American	Diabetes	Breast and lung (females) cancer
	Cervical, liver, lung (males), pancreatic, and stomach cancer	Heart diseases
	Depression (females)	Osteoporosis
Puerto Rican	Diabetes	
	Liver cancer	
	Heart diseases	

All population categories other than Hispanic/Latino are non-Hispanic

^aBased on average risk for majority of older Americans

Sources: Hummer et al. (2004). The following reviews of the literature from Stanford GEC: McBride et al. (1996), McCabe and Cuellar (1994), Richardson (1996), and Villa et al. (1993)

As there is great variation by acculturation level and other variables in the degree to which elders in the US in specific ethnic populations believe in and practice these culturally based beliefs, providers should use the knowledge as general background but not assume that any one person adheres to the systems from their native culture or religion.

Cohort Experiences

Another set of information important for geriatric cultural competence is the knowledge of what elders are likely to have experienced in their lifetimes. In taking a health and social history, assessing the risk for certain health problems, or providing patient education, some knowledge of the experience of the patient's cohort in issues such as discrimination, trauma, and migration provides important background. This is especially true in long-term care, where knowing, for example, that fear of showers may be related to dementia patients' experience as holocaust survivors, or the importance older Russian residents place on tiny pieces of paper may be related to the fact that they are the only surviving possessions from a lifetime of forced migrations.

In the effort to make this information more accessible, core faculty members from SGEC have developed summaries of the cohort experiences of elders from eight ethnic populations in the US (Yeo et al. 1998).

Skills

Culturally Appropriate Respect

Especially because other cultures tend to value age and elders more than is found in mainstream America, the expectation for respectful courteous behavior toward older patients may be high. However, it may be difficult for

providers to know what behavior is considered respectful in various cultures. Some of the indications of respect that vary by culture include: shaking hands, bowing, eye contact, personal conversation before business conversation, and where and how someone may be touched. In most cases (and especially with African American elders because of the indignities and disrespect their cohort has experienced), it is recommended that providers address elders by Mr. or Mrs. unless they are given permission to do otherwise, although in some Southeast Asian cultures, the most respectful greetings of elders use family terms such as “grandmother.” It is extremely important for reception staff also to be trained to show respect and call elders by “Mr.” and “Mrs./Ms.” because they are usually the first interactions older patients will have. To learn the appropriate respectful skills, cultural guides and bicultural interpreters can be extremely valuable.

Younger members of the family frequently bring elders in for health care appointments, and it is very easy for providers to talk directly to them rather than to the elders themselves, especially if only the younger ones speak English. This, however, is frequently seen as disrespectful by both the elders and their adult children.

Communication

Skills in a number of other communication issues are also important for providers.

Use of Interpreters Because of the large proportion of foreign-born elders among Asian and Latino populations, providers need to be prepared to offer and appropriately use trained interpreters. Appropriate use would include orienting the interpreters to the plan for the encounter, looking at and talking to patients rather than the interpreters, and asking the interpreters for help in understanding any cultural issues that come up.

If trained interpreters are not available and there is no other choice but to use family members (not children), they can be oriented briefly to make the interactions more effective. This would include: assuring the family member that his/her own opinion and information about the elder’s condition is important to hear after the provider talks to the elder; asking the family member to translate everything the elder says without comment to the extent the family member is able; asking the family member to let the provider know if there are terms that are not familiar to him/her so that they can be said another way. Unless the elder is cognitively impaired, it is important that he/she understands the recommendations the provider makes, and not just the family member. Writing instructions down in English makes it possible for the elder to have them translated by other members of the family as well if there are any questions about it. It should be noted that in some cultures, modesty values make it unacceptable to talk about some private health issues (e.g., gastrointestinal and genitourinary) in the presence of family members of the opposite sex.

Nonverbal Communication Gestures and other nonverbal forms of communication can be problematic, sometimes without the provider knowing it. For example, certain common American gestures (e.g., the upcurled index finger requesting someone to “come here”) are offensive because they are associated with communicating with animals in some cultures. Even worse, some are considered very insulting (e.g., showing the sole of a shoe to someone in some Arab cultures). It is highly recommended that providers working with elders who are less acculturated to the mainstream US culture ask cultural guides about particular nonverbal communication issues.

Explanatory Models of Illness

Eliciting an older patient’s perception of her own condition can be extremely helpful in helping providers understand the cultural beliefs involved and what may be acceptable as management strategies. These perceptions, known as explanatory models, and their importance, were described in a pioneering article by Kleinman et al. (1978) that has become a classic in the literature. Being able to understand and incorporate elders’ explanatory models in recommendations is thought to increase patients’ “compliance.” Questions such as “What do you call your condition?” and “What do you think caused your condition?” can be used to help elicit these perceptions.

For a more comprehensive discussion and recommended techniques, see Module 4 in the Core Curriculum of the web-based Curriculum in Ethnogeriatrics (Yeo 2001).

Physical Examination and Assessment

In many cultures, it is inappropriate to have a provider of the opposite sex, especially when it involves physical examinations. This is especially true among Afghan American elders, and others from conservative Muslim cultures (Morioka-Douglas et al. 2004). As there are portions of the body that are inappropriate for providers to touch in some cultures, it is safer to explain the procedures in physical exams and ask permission before beginning.

Another major issue in assessments is the use of standardized measures of cognitive status and depression that may not be appropriate because of language or literacy level. It is extremely important to have versions in the elders' preferred language, preferably versions that have been validated for those populations. The commonly used cognitive screening measure, the Mini Mental Screening Exam, is available in more than 40 languages online at <http://www.minimental.com>. Likewise, translations of the Geriatric Depression Scale commonly used to screen for depression is available at <http://www.stanford.edu/~yesavage/GDS.html>. However, a large proportion of older adults from a number of ethnic backgrounds (e.g., Mexican American) did not have the opportunity to go to school at all, and many others had an elementary education or less, so that translations are not adequate if elders are not able to read them even in their preferred language. In those cases, the screens need to be administered orally. Other resources on cross-cultural assessments are found in Module 4 of the Curriculum in Ethnogeriatrics (Yeo 2001) and the book *Ethnicity and the dementias* (Yeo and Gallagher-Thompson 1996).

End of Life Care

There are many culturally relevant issues involved in appropriate care of terminally ill elders. Provider skills are needed to ascertain preferences for life-sustaining treatments among elders in cultures where families are expected to make those decisions. It is not uncommon for families to request that elders not be told they have a serious or life-threatening illness in order to protect them from bad news or giving up hope. Hospice care and/or advance directives are seen as inappropriate by some families because death is based on God's timing. In others, such as among African Americans, preference for all possible aggressive treatments stems from lack of trust in the health care system due to centuries of discrimination in health care. Understanding and learning to respond appropriately to these varied needs requires the development of skills not frequently taught in health care training programs.

Conclusion

In order to meet the challenge of the impending ethnogeriatric imperative, it is imperative that the US public health community prepare itself quickly by educating health care organizations and providers. This should take the form of assisting them in understanding the need for, and complexities of, providing accessible and culturally appropriate care to the older Americans from widely diverse ethnic backgrounds.

Acknowledgment

This work was partially supported by a grant from the Bureau of Health Professions, Health Resources and Services Administration, for a Geriatric Education Center.

References

- Adler R, Kamel H (2004) Doorway thoughts: cross-cultural care of older adults. American Geriatrics Society. Jones & Bartlett, Boston
- Anderson NB, Bulatao RA, Cohen B (eds) (2004) Critical perspectives on racial and ethnic differences in health in late life. The National Academies Press, Washington, DC. www.nap.edu
- Brach C, Fraser I (2000) Can cultural competency reduce racial and ethnic health disparities: a review and conceptual model. *Med Care Res Rev* 57(Suppl 1):181–217
- Cross TL, Bazron BJ, Dennis KW, Isaacs MR (1989) Towards a culturally competent system of care: a monograph of effective services for minority children who are severely emotionally disturbed. CASSP Technical Assistance Center, Georgetown University Child Development Center, Washington, DC
- Federal Interagency Forum on Aging Related Statistics (2000) Older Americans 2000: key indicators of well-being. Federal Interagency Forum on Aging Related Statistics, Hyattsville, MD
- Hummer RA, Benjamins MR, Rogers RG (2004) Racial and ethnic disparities in health and mortality among the US elderly population. In: Anderson NB, Bulatao RA, Cohen B (eds) Critical perspectives on racial and ethnic differences in health in late life. The National Academies Press, Washington, DC
- Institute of Medicine (2002) Unequal treatment: confronting racial and ethnic disparities in health care. National Academy Press, Washington, DC
- Kleinman A, Eisenberg L, Good B (1978) Culture, illness, and care. *Ann Intern Med* 88:251–258
- Lavizzo-Mourey R, MacKenzie E (1996) Cultural competence: essential measurements of quality for managed care organizations (editorial). *Ann Intern Med* 124:919–921
- McBride M, Morioka-Douglas N, Yeo G (1996) Health and aging: American Asian and Pacific Islander American elders. Stanford GEC Working Paper, Stanford, CA
- McCabe M, Cuellar J (1994) Health and aging: American Indian and Alaska Native elders. Stanford GEC Working Paper, Stanford, CA
- Morioka-Douglas N, Sacks T, Yeo G (2004) Issues in the care of Afghan American elders: insights from the literature and a focus group. *J Cross Cultural Gerontol* 19:27–40
- Office of Minority Health (2000) Assuring cultural competence in health care: recommendations for national standards and an outcomes-focused research agenda. Federal Register, December 22, 2000, pp. 80865–80879.
- Richardson J (1996) Health and aging: African American elders. Stanford GEC Working Paper, Stanford, CA
- Schneider EC, Zaslavsky AM, Epstein AM (2002) Racial disparities in quality of care for enrollees in Medicare HMOs. *J Am Med Assoc* 287:1288–1294
- Schulman KA, Berlin JA, Harless W, Kerner JF, Sistrunk S, Gersh BJ, Dubé R, Taleghani CK, Burke JE, Williams S, Eisenberg JM, Escarce JJ (1999) The effect of race and sex on physicians' recommendations for cardiac catheterization. *New Engl J Med* 340:618–626
- Villa M, Cuellar J, Gamel N, Yeo G (1993) Health and aging: Hispanic American elders. Stanford GEC Working Paper, Stanford, CA
- Yeo G (ed) (2001) Curriculum in ethnogeriatrics: core curriculum and ethnic specific modules. Stanford Geriatric Education Center, Palo Alto, CA. www.stanford.edu/group/ethnoger.
- Yeo G, Gallagher-Thompson (eds) (1996) Ethnicity and the dementias. Taylor & Francis, New York
- Yeo G, Hikoyeda N, McBride M, Chin S-Y, Edmonds M, Hendrix L (1998) Cohort analysis as a tool in ethnogeriatrics: historical profiles of elders from eight ethnic populations in the United States. SGEN Working Paper Series Number 12. Stanford Geriatric Education Center, Palo Alto, CA. sgec.stanford.edu



4 Legal Aspects of Aging

Janet L. Lowder · Sandra J. Buzney · Catherine M. French · Sana Loue

Introduction

Age is one of the defining criteria for a number of protections and benefits that our society has conferred upon older citizens. Yet one of the first challenges in identifying legal issues unique to older individuals is defining the age at which one is considered an “older” person. In many ways, it is a relative term based on behavior, physical status, and attitude, as well as chronological age. Many would find it shocking to use age 50 as the demarcation line, yet that is the age used as a membership criterion for AARP (formerly called the American Association of Retired Persons). Twenty-five percent of the US population is age 50 or older; it is important to identify the legal issues that this group has in common with younger adults as well as issues that may be more pressing, if not unique, to this segment of the population.

Some of the protections and benefits that our society confers upon older citizens include protective services to investigate allegations of abuse or neglect, public benefit programs for which one can qualify by being a certain age or being permanently disabled (as well as meeting financial criteria) such as Medicare, and eligibility for retirement programs and Social Security.¹ At age 50, the amount that can be contributed to various types of private retirement plans begins to increase so that the individual has the opportunity to “catch up” and build up the balance put away for retirement. Moreover, reaching a specified age, which is dependent to some extent on the specific type of retirement plan, is one of the conditions under which withdrawals can be made without penalty. In fact, for traditional Individual Retirement Plans (IRAs), an individual must start receiving periodic distributions by 1 April of the year following the year in which he or she reaches age 70-1/2 or a severe tax penalty will be imposed (CCH 2006).

Aging also brings an increased risk of illness, incapacity, and death, although none of these misfortunes are exclusive to older individuals. Although adults of all ages should consider appointing surrogate decision makers for financial matters and health care decisions, taking control of one’s future in this manner becomes more important as individuals age. If incapacity strikes, an individual may not be able to manage financial or personal affairs and may not be able to make a knowing decision about who to appoint to make these important decisions. Much like insurance must be purchased before the need to make a claim arises, choices about surrogate decision makers must be made and formalized before they are actually needed. If the need for a surrogate decision maker or “agent” arises but no one has been formally appointed to fill the void, legal proceedings, such as appointment of a conservator or legal guardian, may be necessary.

Tools for Surrogate Decision Making

As stated earlier, the opportunity to and benefit of appointing surrogate decision makers for financial and health matters is not unique to the older population. The risk of suffering a chronic illness, debilitating physical condition, and/or mental deterioration does increase with age, albeit probably not as dramatically as stereotypes of aging might suggest. Tragedy can strike at any age, and everyone can have peace of mind that one’s wishes will likely be honored if tragedy strikes. Planning tools, such as powers of attorney, revocable living trusts, and advance medical directives allow an individual to have some control and independence in an otherwise uncontrollable

¹ Age is not the only criterion for these programs, but it certainly is an important one.

situation. They empower an individual to choose a surrogate decision maker and provide direction as to how their personal, financial, and/or medical issues should be handled in the event of incapacity. If an individual is responsible for the care and support of a spouse or child with a disabling condition, planning in advance can offer protection for those who are emotionally, physically, and/or financially dependent.

Capacity is a medical and legal term referring to a person's mental competence and ability to make informed decisions regarding medical, personal, financial, and/or legal matters. Potentially disabling conditions may affect an individual's capacity, such as mental retardation, severe mental illness not controlled by medication, brain injury, chronic substance dependence, or a physical illness that severely impairs awareness of the environment, intellectual functioning, and/or reasoning abilities.

Incapacity and disability are not equivalent terms. An individual is not incapacitated simply by reason of age or a potentially disabling diagnosis. One's capacity can vary over time and is dependent on the circumstances and the task involved. Some areas of decision making require a higher level of comprehension and reasoning than others. Therefore, a person with a condition affecting his/her capacity may be able to make some decisions but not others. A person with capacity who has a disabling condition may choose to execute documents, which allow others to advocate and act on his/her behalf regarding such matters as education issues, vocational training, and applying for public benefits. Thus, while planning tools are particularly helpful in the event of incapacity, they are flexible enough to address a broader range of issues.

Besides offering flexibility, planning tools are advantageous because they are generally more cost-effective than proceedings requiring court oversight. It is important to keep in mind that state law governs planning tools, meaning that states may differ on the types of planning tools allowed, the terminology used, the requirements to execute legal documents, and the circumstances in which they are effective. Therefore, it is necessary to assure that procedures and documents are in compliance with state law.

Case Examples

Before delving into the technicalities of each planning tool, the following cases illustrate some of the unforeseen circumstances that planning tools address and the potential consequences of a lack of planning.

Ms. T

Ms. T, age 51, was involved in a sporting accident, which resulted in a traumatic brain injury. At the time of the accident, she was living independently and had recently left a job with health care benefits to start her own business. During the 2 weeks that she was hospitalized in intensive care, hospital staff did communicate with her parents even though Ms. T did not have a health care power of attorney in effect. Her parents advanced funds to pay her immediate bills, but again, had no legal authority to handle her finances. Fortunately, Ms. T's condition improved to the point where she did have the capacity to execute a durable general power of attorney, health care power of attorney, and living will. Now, her father can request information about her health care benefits, collect information about her finances, pay her bills, and communicate with her physicians.

Mrs. H

Mrs. H never executed a durable general power of attorney or health care directives. She was the parent of three adult children, including John, who was permanently disabled due to a combination of mild cognitive impairment and physical limitations. When she remarried, she and her second husband bought two very modest houses—one in which they resided and one across the street for John and his wife.

Both houses remained titled in the couple's name and passed to Mrs. H upon her husband's death. Mrs. H's health had deteriorated to the point where she was physically and mentally incapacitated and her daughter was

appointed as Mrs. H's guardian of person and estate. Mrs. H eventually was placed in a nursing home. She had inadequate funds to pay for her care, and her daughter applied for Medicaid on her behalf. If she had executed a durable general power of attorney with provisions allowing her agent to make gifts of her finances and negotiate all financial transactions, including executing a deed, the individual appointed as her agent would have had the authority to transfer the home that John lived in to him, as Mrs. H and her husband intended.

Mr. R

Mr. R was a 70-year-old individual with severe diabetes and end-stage renal disease that was treated by hemodialysis. Mr. R's primary caregiver was his ex-wife. He was also survived by three children, the oldest of whom was a young adult.

Mr. R did not execute any health care directives while he had the mental capacity to do so. As his health deteriorated, he developed an ulcer on his foot and eventually required a below-the-knee amputation. The surgical site did not heal, resulting in the need for further surgery. Mr. R had told his ex-wife that he did not want aggressive care. After enduring several surgeries, he asked to be left alone. However, his status had deteriorated to the point where he lacked the mental capacity to make informed decisions about his health care. His eldest child was recognized as his legal decision maker by the medical team even though no formal guardianship proceedings were initiated. She could not accept that Mr. R's prognosis was very poor and held out hope that he would receive a kidney transplant. Therefore, she wanted all means taken to prolong his life. Thus, hemodialysis and aggressive care continued until Mr. R's death. Had he executed a health care power of attorney and living will naming his ex-wife as his agent, she would have been able to direct the medical team to discontinue dialysis and institute comfort measures, which would have been consistent with his expressed wishes.

Mrs. E and Mr. J

For various reasons, many individuals who are in a committed relationship with another adult never formalize their relationship through marriage. One such couple in their 80s have lived together as man and wife for a number of years but never married due to financial concerns. There was some friction between Mrs. E's adult children and Mr. J. Fortunately, they both executed durable general powers of attorney, health care powers of attorney, and living wills and appointed each as the other's agent. When Mrs. E. became ill, Mr. J was able to access her health care information and make decisions on her behalf when she could no longer do so. He was also able to handle her financial matters. Without these legal documents in place, Mrs. E's children would have had priority for directing their mother's medical care and would have also had priority if appointment of a legal guardian was required. Due to the poor relationship, the children would have been able to exclude Mr. J from any involvement in Mrs. E's care or finances, even though his presence was a great comfort to her.

Planning Tools

Each of the planning tools discussed below—powers of attorney, revocable living trusts, advance medical directives, and guardianships and conservatorships—provides various benefits, and is characterized by various limitations. [▶ Table 1](#) provides a summary of the uses and limitations of each of these mechanisms, which are discussed in significant detail below.

Powers of Attorney

A power of attorney is a legal document that allows a person (the “principal”) to name another person (the “agent” or “attorney in fact”) to act in place of the principal. The power of attorney must be signed while the

■ Table 1

Comparison of features of various advance planning mechanisms

Feature	Powers of attorney	Revocable living trusts	Advance medical directives	Guardianships/ conservatorships
Mechanism	Allows individual (principal) to name another person (agent) to act in his/her place	Like a contract for management of one's assets; allows individual to manage own assets for his/her own benefit	Three basic types: health care power of attorney, living wills, DNR orders	Available when other planning mechanisms have not been utilized
Duration	May be effective upon signature or at time or event, depending upon type of power of attorney and wishes of principal	Effective at time of signature		Varies by individual situation
Capacity	Must be signed while principal has capacity	Must be signed while individual has capacity	Must be signed while principal has capacity	Individual lacks capacity in some or all aspects of functioning
Court involvement	Varies by state	None in most circumstances	None in most circumstances	Required to establish mechanism; ongoing court monitoring in most states
Scope	May be unlimited or restricted	Allows individual to designate which assets to be part of trust; trust governs distribution of property during period of incapacity and following death	Varies by state and type of advance medical directive	Varies by state and mechanism; guardianships and conservatorships may be over person, estate, plenary, limited, or emergency only depending on state law and circumstances
Revocability	Revocable as long as principal is alive and retains capacity	Revocable while individual still alive and has capacity	Revocable while principal is alive and retains capacity	May be terminated by court only

principal has the capacity to understand the purpose of the document. Therefore, a power of attorney is not a good tool when the mental capacity of the person is questionable. When a person has periods of lucidity, such as an individual with Alzheimer's disease, it is important to have evidence that the principal understood and voluntarily signed the document.

The principal grants authority to the agent to act in the principal's place. There is no court supervision of the agent in many states. The principal chooses the agent, but some states limit the principal's choice to certain categories of persons, such as family members (Guardianship Over the Elderly 2003). The principal should also consider choosing a successor agent in case the primary agent is unable to act. The authority of agent can be unlimited or restricted to handling specific matters, and is defined in the document itself. The principal has full power to continue handling his/her own affairs while the power of attorney is in effect.

There are three types of powers of attorney: (1) general, (2) durable, and (3) springing. The general power of attorney is effective upon signature, and the agent's authority lapses if the principal becomes incompetent. A principal may nominate a guardian for himself or herself in the event of incompetency, which the Court would formally need to approve during a guardianship proceeding. The general power of attorney is most useful, however, in authorizing the handling of short-term matters when the principal is not available rather than planning for future incapacity.

The durable power of attorney is a good tool for planning for future incapacity because it also is effective upon signature but survives the later disability or incompetence of the principal. All states have statutory provisions that allow the creation of a durable power of attorney but states differ in the scope of power allowed (Guardianship Over the Elderly 2003). There are two basic types: (1) general and (2) limited or special. A durable general power of attorney grants the agent broad powers, allowing the agent to act as the principal could act in situations. It is advisable to have an attorney prepare a durable general power to assure that it serves the purposes that the principal intended and complies with state law, and is properly executed. A limited or special durable power of attorney grants the agent only those powers specified in the document. For example, there are durable powers of attorneys for property and health care (which is also considered a type of advanced directive).

A durable general power of attorney may be used to avoid guardianship of the estate and probate court jurisdiction over the principal's financial matters. Sometimes, however, guardianship cannot be avoided. This may happen for a number of reasons: the agent is no longer capable of acting and there is no successor; the agent does not have authority to act in a particular situation; the agent abuses his/her powers; or other interested parties are dissatisfied by the agent's decisions and seek removal by guardianship. When a guardianship is created, some states terminate the durable power of attorney but a significant number of states do not, instead requiring accountability of the agent to the guardian (Smith 1996).

The springing power of attorney becomes effective at either a later specified date or upon the occurrence of a specific event as defined in the document, such as the disability, incapacity, or adjudged incapacity of the principal. Adjudged incapacity should be avoided if the goal is to avoid probate court proceedings. The principal may specify the meaning of incapacity and who will make that determination (this should be a person other than the agent). Although no state statute expressly prohibits this type of power, some are silent on this type of power (Guardianship Over the Elderly 2003).

There are many advantages to using powers of attorney. Powers of attorney are inexpensive, revocable (as long as the principal has the capacity to revoke it), does not require any accounting to the probate court, and the principal retains the ability to manage affairs while he or she is able to do so. There is a lot of flexibility, as the principal can choose the decision maker, the scope of power, and the time and method of deciding when the agent takes over (Guardianship Over the Elderly 2003). There are also disadvantages to powers of attorney. Financial institutions and companies are not obligated to honor a power of attorney. A few insurance companies, Social Security Administration, and IRS may disregard the power of attorney. Also, despite the fact that the agent is a fiduciary, there is a potential for abuse, as the agent may mismanage or take assets. To safeguard against abuse, because of the flexibility of powers of attorney, it is possible to write clauses in the document requiring accountings or a bond/insurance.

Revocable Living Trusts

A trust is essentially a contract for the management of one's assets.² A "grantor" or "settlor" establishes the trust and funds it, the "trustee" manages and administers the trust, and the "beneficiary" receives the benefit of the trust assets. In a "living trust," or inter vivos trust, all three parties may initially be the same individual. The grantor may also designate successor trustees and remainder beneficiaries who receive the benefit of the trust assets after his/her death. A revocable living trust can be changed or canceled at any time, while the grantor has the capacity to do so.

An individual who has capacity may establish a trust and transfer his/her property to the trustee. This property can include land, stocks, bonds, vehicles, and cash. Retirement funds such as IRAs or 401(k) plans cannot be held

² It is important to note that a "living trust" or "revocable trust" is one type of trust arrangement. There are other mechanisms and ways to title assets which will minimize the need for appointment of a guardian to manage an incapacitated individual's funds. For example, by authorizing a signor or naming a co-owner of an asset, another individual will also be authorized to access the funds in the account.

in a trust; an agent under a durable power of attorney will still be needed to access or make elections concerning these assets. While an individual remains capable, he or she may act as the initial trustee and manage the trust for his/her own benefit, as the primary beneficiary. If that individual becomes incapacitated, the successor trustee is able to assume the management of the assets for the now incapacitated individual's benefit. Thus, the grantor, while no longer the acting trustee, remains the beneficiary.

A living trust should avoid the necessity of guardianship in the event of the grantor's incapacity. For all practical purposes, living trusts are easier, faster, more convenient, and allow greater privacy than guardianship (Summers 1996). In the event, however, of guardianship proceedings, state laws regarding trusts generally exempt the trust assets from the guardianship estate. Thus, if a guardian of the estate is appointed, he or she will have control over the assets that were not transferred into the trust and must work with, but not replace, the successor trustee (Summers 1996).

Another advantage of living trusts is that when the incapacitated individual dies, the trust agreement will govern the distribution of the property held in trust. Depending on the terms of the trust agreement, all assets may continue to be held in trust or may be distributed to the remainder beneficiaries. While a trust does not avoid federal or state estate taxes, it does avoid probate administration.

Advance Medical Directives

Advance medical directives communicate one's health care wishes. There are three basic types of advance directives: health care power of attorney, living wills, and do not resuscitate (DNR) orders. Living wills and health care power of attorneys are sometimes supplemented with a "values history," which includes an explanation of personal values related to medical care (Doukas and Reichel 1993). The majority of states recognize both the health care power of attorney and living will, although states vary in what they are called, the scope of decision making allowed, restrictions, and how they are created (Sabatino 2003).³ New York is one state that does not recognize living wills. Most states provide forms to create advance directives, although the majority of these states allow personalized deviations from provided forms (Sabatino 2003). If one executes "standard" forms issued by a state agency, there is usually no need for the involvement of an attorney, and the advanced directive is generally honored immediately. In contrast, if one wants to create an individualized document, it would be wise to consult an attorney to assure that the document complies with state law and will serve its intended purpose. An individualized directive should be honored, but may need to be reviewed by the medical facility's legal department before the decision is made.

Individuals must be competent when creating advance directives, and witnesses are usually required. Advance directives are usually not effective until the individual becomes incompetent, but some states allow immediately effective directives (Sabatino 2003). A competent individual, however, can always veto the agent or revoke the directive (Sabatino 2003).

A general power of attorney for health care, also called the health care proxy, allows a person, the "principal," to delegate any or all health care decisions to another, the "agent." The durable health care power of attorney survives incompetency and may be narrow, such as for a particular surgery, or broad, including both routine care and end-of-life decisions. (See the "Powers of Attorney" section for a thorough discussion of powers of attorney.) Some states limit who may be designated as the agent (Guardianship Over the Elderly 2003). A significant number of states do not allow a health care provider or facility to be an agent; a few states prohibit physicians (American Bar Association Commission, 2002). The agent makes health care decisions consistent with the principal's wishes. Minimally, the principal should at least express generalized preferences for the level of care in medical situations, such as no heroic measures, only comfort care, or to aggressively pursue all potential life-saving measures

³ The testimony of Penelope A. Hommel contradicts the "both" part of this statement (Guardianship Over the Elderly 2003, 109).

(Krohms and Summers 2002). Optimally, to guard against possible abuse by the agent, it is wise to include specific instructions regarding wanted and unwanted treatments (Guardianship Over the Elderly 2003). Even if instructed by the principal, however, some states limit the agent's power on matters such as mental health admission and treatment, psychosurgery, electroconvulsive surgery, sterilization, abortion, pregnancy, and life-sustaining procedures unless expressly authorized (American Bar Association Commission on Legal Problems of the Elderly 2002).

A living will is a written instruction to doctors about end-of-life treatments; although no third party is necessary to effectuate it, state law may require the physician to notify individuals named in the document, who will then have a limited time in which to object to the termination of life-sustaining treatment. In the majority of states, a living will authorizes medical staff to act, or not to act, in situations involving life-sustaining treatment of "terminal conditions" (Johns 2004; Guardianship Over the Elderly 2003). New York, however, does not recognize living wills. Some states also allow a living will to apply to individuals in a persistent vegetative state (Guardianship Over the Elderly 2003). Terminal condition is defined in statutes, and usually specifies that death must be imminent or expected to occur in a relatively or reasonably short time (Johns 2004, p. 131). Some statutes allow a person to name someone in the living will to make health care decisions when the person is terminal or in a persistent vegetative state (Guardianship Over the Elderly 2003). Other common features among state statutes include the right to personalize instructions, the need for one or two doctors to certify that the individual is terminally ill, the requirement of a doctor to honor the living will or transfer care, the requirement of a doctor to place a known living will in the medical file, the requirement of two witnesses or a notary public to the signing, and immunity from liability for doctors and facilities for following the living will (Doukas and Reichel 1993).

Typically, the living will states the circumstances in which life-sustaining treatment should be withheld or withdrawn and specifies what life-sustaining treatment the individual wants or does not want. States, however, have different definitions of life-sustaining treatment. For example, some states explicitly include a right to withdraw or withhold artificial nutrition and hydration, while others are silent on the issue, and a few prohibit such a right (Guardianship Over the Elderly 2003). While a living will should be written, statements regarding the withholding of life-sustaining procedures to family members may constitute an oral living will if determined by a court (Johns 2004; Doukas and Reichel 1993). Some states do not allow a living will to be operative if the principal is pregnant (Doukas and Reichel 1993).

There are several reasons why a health care power of attorney is preferable to a living will, as long as there is a trusted agent. Unlike a health care power of attorney, living wills have a limited functionality, applying only to terminal conditions or when a person is permanently unconscious (Guardianship Over the Elderly 2003). In contrast, most medical decisions for incompetents involve more routine issues. Living wills are also generalized and therefore can be difficult for medical staff to interpret and apply in actual medical circumstances where unforeseeable factors are involved. An agent, on the other hand, acts as an interpreter of the principal's wishes. In cases where artificial hydration and nutrition are needed, some states do not allow the withdrawal of sustenance under the terms of a living will if such withdrawal would cause death, but most states specifically authorize the agent to withhold artificial hydration and nutrition (Krohms and Summers 2002).

Ideally, it is best to have both a living will and a durable health care power of attorney, as the living will acts as a back up if the agent is unavailable in an emergency, and guides the agent when he or she is available. If a person normally spends time in two different states, it may be worthwhile to execute standard health care directives for both states. Although there is an emerging trend towards uniformity among states in regard to advance directive laws, current laws present obstacles to uniformity. These obstacles include the minority of states with state-specific mandatory educative warnings to those executing a durable health care power of attorney or mandatory forms (Sabatino 2003), and the minority of states that lack an explicit statutory provision recognizing valid out-of-state advance directives. Although national uniformity of the law is not necessary to ensure recognition among states, it would encourage more meaningful recognition in that the advance directive would be interpreted as the individual intended. Currently, a state with reciprocity may apply different meanings to the language in directives. For example, an individual in one state may use general language granting the agent the power to make all health

decisions, intending to include decisions about withdrawing or withholding sustenance. In the state where execution takes place, this intention is presumptively honored. Yet, if this individual travels to another state that requires an express statement regarding withdrawing or withholding sustenance, the individual's intention cannot be honored (Sabatino 2003).

A DNR order is another kind of advance directive. A DNR order instructs another who assists a person in severe medical distress to withhold life-saving medical intervention, such as cardiopulmonary resuscitation (Johns 2004). States differ on the circumstances under which a DNR is permitted (Krohm and Summers 2002). A vast majority of states allow both in- and out-of-hospital DNR orders (Krohm and Summers 2002). Some states prohibit a guardian's consent to a doctor's DNR order without prior court approval (Summers 1996; Krohm and Summers 2002). Within states, there are usually different regulations governing out-of-hospital and in-hospital DNR protocols (Krohm and Summers 2002). In-hospital DNR orders are usually placed in admission documents and staff are notified and directed as such (Johns 2004, p131). Out-of-hospital DNR orders are helpful in emergencies, where there is no time to locate and interpret other kinds of written advance directives (Krohm and Summers 2002). This is because DNR orders are typically more visible; states may issue DNR bracelets or prescribed forms on colored paper (Krohm and Summers 2002). Yet, there is a greater risk, as compared to in-hospital DNR orders, that the execution of a DNR order is not communicated (Johns 2004, p131).

In addition to living wills, health care power of attorneys, and DNR orders, a growing number of states are allowing declarations of preferences for mental health treatments, also called psychiatric advance directives. Legislatures created these statutes because of concern that existing directives did not address the specific treatment needs of those with mental illness (National Mental Health Association n.d.a). It is important to note, however, that some states specifically do not allow certain types of mental health treatment in their advance directive statutes (NAMI n.d.b; National Mental Health Association n.d.a). Psychiatric advance directives provide specific instructions regarding treatment and/or designate a proxy to make decisions regarding treatment in the event of incapacity. An increasing number of states require that a psychiatric advance directive can only be revoked when the individual is competent or in remission (National Mental Health Association n.d.b; Krohm and Summers 2002). Thus, in a middle of a psychiatric crisis, a doctor may continue to treat regardless of how ardently the individual protests (Krohm and Summers 2002). Critics contend that revocation during a crisis should be allowed because it would simply put the individual in a situation similar as if he or she had never executed the directive. A potential compromise is to allow the individual to specify whether or not his/her psychiatric advance directive can be revoked during a crisis (National Mental Health Association n.d.a). Some states specifically provide in statute an automatic expiration date (Krohm and Summers 2002). Because of the novelty of psychiatric advance directives, it is unclear whether or not and under what circumstances they will be legally enforceable (NAMI n.d. b). The National Alliance for the Mentally Ill is advocating support of such directives as a tool of empowerment but also call for ongoing research (NAMI n.d.a). Likewise, the National Mental Health Association (n.d.b) promotes psychiatric advance directives for psychiatric crises.

There are some common misperceptions about advance directives. People often assume that advance directives are only used to specify what treatment is not wanted, but advance directives can be used to direct doctors to use all possible life-saving treatment and provide comfort care. People also often associate advance directives with the elderly, but young adults can have more at stake, for, if there is an unfortunate accident, a young adult may be kept alive for decades in an unwanted condition (Sabatino n.d.).

Although advance directives are an important planning tool, there are some concerns about their implementation. There is fear that a doctor will conclude that if an individual does not have a directive, he or she intended to have life-sustaining treatment administered under all circumstances. Yet, evidence suggests that the real reason people do not create a directive is because of ignorance of available tools, unawareness of its importance, or uncertainty as to how to create it (Smith 1996). There is also concern that if an individual does have a living will, the medical staff may under-treat based on inattentive over-generalizations of the document (Lynn 2003). Yet, even with these concerns, advance directives are particularly helpful when the relationship to the proxy is not legally sanctioned, such as a partner (as in the case example of Mrs. E and Mr. J) or there is an unusual specific preference, such as not to be taken to a particular hospital (Lynn 2003). The documents are only useful if they are

provided to health care professionals, the appointed agents, and made available when an individual seeks emergency room treatment or is hospitalized.

Guardianship/Conservatorship⁴

Guardianship should be considered only when a person has failed to put in place the planning tools described above or circumstances demand a guardian. Guardianship is a legal process in which the court appoints an individual, association, or corporation (the “guardian”) to act on behalf of another who has been declared incompetent or incapacitated (the “ward”). There are several types of guardians, including guardian of the person, guardian of the estate, plenary guardian, limited guardian, and emergency guardian. A conservatorship is a distinct proceeding that might be described as a “voluntary” guardianship for individuals who are physically disabled or infirm but mentally competent. The individual selects the conservator, and asks the probate court to appoint that person and specifies the scope of authority. The individual may discharge the conservator if he or she is dissatisfied with the person or if his/her condition improves. Generally, all other appointment procedures, powers, and duties for a conservator are the same as those of a guardian. In guardianship of the person, the guardian is appointed to have custody and provide for the support or maintenance of a ward. This involves all day-to-day decision making of a personal nature, including arrangements for food, clothing, housing, medical care, and recreation. In guardianship of the estate, the guardian is appointed to manage the finances of the ward in the ward’s best interest. In a limited guardianship, the guardian has powers specifically limited by the court and the ward retains all other rights. An emergency guardian is appointed without a hearing by the court when an emergency exists and a guardian is necessary to prevent injury to the person or estate. An emergency guardianship usually occurs when consent for medical treatment is needed and the individual is unable to make an informed decision on his/her own behalf.

In many states, simply filing a short petition with the clerk, containing personal identifying information and a brief statement of the reasons for seeking guardianship, initiates guardianship (Summers 1996; Krohm and Summers 2002). Notice is then provided to the proposed ward and others as determined by state statute, usually the spouse, parents, adult children, or closest adult relative (American Bar Association Commission on Law and Aging and Hurme 2004c). The party initiating the case bears the burden of proving that the proposed ward is incapable of decision making (Krohm and Summers 2002). The standard of proof differs among states; most require a “clear and convincing” standard, some state statutes are silent on the issue, and a few have standards of “if the court is satisfied,” “preponderance of the evidence,” or “beyond a reasonable doubt” (American Bar Association Commission on Law and Aging and Hurme 2004a). States have different definitions of incapacity but each revolves around all or some of the following elements: functionality; cognition; necessity of guardianship and the risk of harm if no guardianship; and physical or mental conditions of the proposed ward (American Bar Association Commission on Law and Aging and Hurme 2004b). In making its determination of incapacity, the court gives a great deal of weight to medical or psychiatric evidence, but states have different requirements concerning medical documentation and evaluation of the proposed ward (American Bar Association Commission on Law and Aging and Hurme 2006).⁵ The medical evaluation must be current and centers on whether the proposed ward is fully capable, totally incapable, or partially capable of making personal and/or financial decisions. Based on the evidence, the court determines the scope of guardianship, specifically whether it will be limited or full, and then determines who will be appointed as guardian (Summers 1996).

⁴ Some states, following the Uniform Guardianship and Protective Proceedings Act, use the term “guardian” for guardianship of the person, whereas “conservator” is used for the guardianship over the estate—the “ward” in a conservatorship is called a “protected person.” Still other states, such as New York and Ohio, use the term guardianship in its plenary sense, whereas conservatorship is a voluntary proceeding for an individual who is not adjudged incompetent, but needs assistance with their affairs. This article uses the latter terminology.

⁵ For example, Maine requires only that a physician or licensed psychologist evaluate the proposed ward, whereas Kentucky requires an interdisciplinary evaluation by a physician, psychologist, and social worker.

Because a guardianship is a legal proceeding, the proposed ward is entitled to due process protection (National Guardianship Association n.d.a). All states afford notice of the hearing to the proposed ward (American Bar Association Commission on Law and Aging and Hurme 2005). All states allow counsel, but few require the appointment of counsel (Smith 1996; American Bar Association Commission on Law and Aging and Hurme 2004d). Generally, the courts make counsel available to indigent individuals. Most states provide for a guardian ad litem who represents the proposed ward's "best interests," but this person may act as an independent evaluator rather than an advocate (Smith 1996). Some state statutes explicitly allow a jury trial; only one state, Kentucky, mandates a jury trial (American Bar Association Commission on Law and Aging and Hurme 2004a). In practice, however, jury trials rarely happen; a judge will usually conduct a bench trial if the guardianship is contested (Summers 1996). Generally, states allow the proposed ward to compel, confront, and cross-examine witnesses, present evidence, and appeal the determination of the court (National Guardianship Association n.d.a). Thus, all states provide due process but the rights afforded vary state by state.

Unfortunately, in many situations, due process rights are disregarded or minimized in practice. A. Frank Johns, a Certified Elder Law Attorney (CELA), testified in 2003 before the US Senate Special Committee on Aging that empirical research shows that judges arbitrarily and paternalistically adjudicate guardianship proceedings without adhering to statutory due process requirements (Guardianship Over the Elderly 2003). For example, the proposed ward may not even be present at the hearing (Guardianship Over the Elderly 2003). Also, some judges disregard durable powers of attorney, including the ward's nomination of surrogate decision makers (Guardianship Over the Elderly 2003). The recommendations of Wingspan: The Second National Guardianship Conference, held in November 2001, included funding of court investigations at the beginning of guardianship proceedings to guarantee due process protection as a high priority (Guardianship Over the Elderly 2003).

As a result of guardianship proceedings, if the proposed ward is found to be incapable or incompetent, the ward loses legal rights in areas in which he or she has been declared incompetent. The ward may lose the right to: determine living arrangements; make medical decisions; drive; manage, buy or sell property; marry; and/or vote (National Guardianship Association n.d.a). Yet, there are certain rights maintained, including the right to be treated with dignity and respect; the right to privacy; the right to have personal desires, preferences, and opinions considered by the guardian; the right to have explanations of medical treatment; and the right to an attorney and to petition to modify or terminate the guardianship or bring a grievance against the guardian (National Guardianship Association n.d.a).

States usually have minimum requirements to become a guardian. The proposed guardian cannot be a minor, felon, or adjudicated as incompetent (Summers 1996). Some states require advance training or ongoing certification (Summers 1996). The guardian's responsibilities differ based on the type of guardianship. In regards to guardianship of the person, perhaps the most important responsibility is to understand that his/her role is to help and support the ward; the guardian cannot make the ward do anything against his/her own will, unless specified by the court (Summers 1996). When a guardian is faced with a major decision, such as whether to involuntarily commit the ward or consent to certain medical treatment, the guardian should formally petition the court for authorization if possible (Summers 1996). Some states require detailed reports by guardians, while other states have minimal requirements (Summers 1996).

In regards to guardianship of the estate, the guardian is responsible for all real and personal property. Generally, this entails marshalling and protecting assets; obtaining appraisals of property; protecting property and assets; receiving income and making appropriate disbursements subject to court authorization; and reporting to the court (National Guardianship Association n.d.a). Also, a guardian must usually obtain court approval before selling assets (National Guardianship Association n.d.a).

Ideally, a family member or close friend who knows of the person's wishes, beliefs, and values should be appointed as a guardian. Yet, sometimes such a person is unable to serve, and public guardianship is an emerging alternative. Some counties have public guardianship programs that may require that no family or friends are available and/or the ward lacks money to compensate a private, professional guardian. Another growing trend is non-profit guardianship services. Such programs often have hired staff but are primarily dependent on volunteers to act as guardians. Primarily, these nonprofits service indigent clients who lack family members or others to act as guardians, but may extend services to fee-paying clients.

While guardians have significant responsibility, they also acquire power stemming from these responsibilities, which too often leads to abuse.⁶ Because guardianship grants broad power to the guardian and deprives the ward of his/her legal rights, guardianship should be pursued as a “last resort.” In addition to the other planning tools discussed in this article, which are alternatives to guardianship, mediation is another up-and-coming alternative. Mediation involves a neutral facilitator in a nonadversarial forum who assists the family in resolving issues themselves (Guardianship Over the Elderly 2003). Mediation is useful because it addresses the underlying issues, such as caretaker stress or family disputes, that may be entwined with the legal reason the petitioner seeks guardianship (Guardianship Over the Elderly 2003).

Failure to Plan

It is all too common for people to avoid planning for the future, believing that such thinking is morbid, or that such planning is founded on negative thinking, which will bring bad luck, misfortune, and or ill health to the thinker. Unfortunately, a failure to plan may result in unwelcome consequences in both the health and financial contexts that could have been avoided had individuals been willing to contemplate their own potential disability and the inevitability of their own deaths.

Case Examples

The cases of Mrs. S, Mrs. P, and Mrs. Q serve as good examples.

Mrs. S

Mrs. S and her husband have been married for almost 20 years. Several years ago, Mrs. S developed severe chest pain but refused to see a physician, believing that “everything would be alright” and that “no news is good news.” The pain gradually increased and became more widespread. Mrs. S finally agreed to see a physician when she began to experience difficulty breathing due to the severe pain. Following a physical examination and a sequence of many tests, Mrs. S was diagnosed with lung cancer, which most likely was associated with her almost-lifelong heavy smoking. The cancer was found to have already metastasized to the ovaries by the time Mrs. S presented to the physician.

Surgery, radiation, and chemotherapies were utilized in an attempt to reduce the spread of the cancer. During this entire time, which spanned close to two years, Mrs. S refused to execute powers of attorney. She believed that her husband would be able to make health care decisions for her without having to execute such documents, and her husband believed that thinking about such things was morbid and depressing. Mrs. S became somewhat hysterical every time the subject was raised.

⁶ In Michigan, a 2003 state audit of five probate courts found widespread financial abuse by guardians, such as late payment of bills, lack of accounting, and borrowing interest-free loans from the estate. A Washington Post article reported that, since 1995 in Washington, DC, one of five guardians have gone years without reporting to the court, and in more than 24 cases, guardians or conservators have taken or mishandled money (Center for Social Gerontology 2004). A 2004 study by the United States Government Accountability Office (2004) shows that although all states require oversight, generally in the form of personal and accounting reports, fewer than half of the states require courts to actually review the submitted reports. Most of the courts surveyed in this study blamed insufficient funds for proper oversight. The lack of coordination between state courts and federal agencies perpetuate abuse. State courts and federal agencies do not systematically notify each other when a person is appointed a guardian or when a guardian or representative payee is abusing funds. Thus, an identified abuser in one system may remain in charge of finances in the other system. Also at issue is that the incidence of guardianship or representative payee abuse is unknown, in part because courts do not track basic information such as the number of guardians assigned. The Government Accountability Office study calls for both systematic information sharing and compilation of national data on the incidence of abuse.

Unfortunately, during this time, Mr. S was the victim of a fatal car crash. Mrs. S' condition steadily worsened, with the cancer metastasizing to an area near her spine. She was no longer able to understand what was happening around her and lacked capacity to make any decisions about life-saving procedures, the use of or withdrawal of a feeding tube, or maintenance in a hospital or hospice. Mr. and Mrs. S had had only one child, who suffered from mental retardation and could not be relied upon to make decisions for Mrs. S. Mrs. S had been estranged for many years from her only sibling, a sister. Given a choice, Mrs. S probably would not have wanted her sister to be recruited to make health care decisions for her. She most likely would have preferred that one of her closest long-term friends be enlisted to make such decisions, because the friend was aware of the values that Mrs. S held most dear, and she and Mrs. S had discussed many times how they would like to see their lives end in the event of an incurable or disabling condition. However, the governing state statute gave authority to Mrs. S' sister to make such health care decisions for her in the absence of legal document designating an agent or a relative with higher priority, such as a living spouse.

Mrs. P

Mrs. P has always been very sympathetic to the financial woes of her grandson. Two years ago, he encouraged her to transfer title in her two-family home to him alone and asked her to add his name to several bank accounts, which he then depleted. She told other family members that she felt very pressured to do these things and did not realize that her grandson would be able to withdraw money at will. However, when a social worker from the county protective services agency interviewed Mrs. P in response to a report made by another relative who suspected financial exploitation, she stated that she acted voluntarily because she did not want her grandson to get into legal trouble.

Mrs. P now recognizes that her actions were a mistake. Because she understood those actions at the time and acted voluntarily, there is little likelihood of recovering the transferred funds. However, to minimize the likelihood that she will give her grandson any additional money or direct access to her assets, she gave her daughter durable power of attorney so that the daughter can transfer funds to new accounts open in Mrs. P's name only and have the statements mailed to the daughter's home. Her grandson will not know where Mrs. P holds her remaining funds unless she decides to tell him and will not have direct access to the accounts.

Had Mrs. P. established a living trust much earlier, named another individual to serve as trustee, and transferred her house and other assets into the trust, Mrs. P would have had the benefit of her money and home without the ability to transfer any trust assets to her grandson, in response to future requests for assistance.

Mrs. Q

Mrs. Q also had a grandson who pressured her to assist him financially. However, by the time that others discovered that most of her funds had been depleted by "gifts" to her grandson, she did not have the capacity to execute a durable power of attorney or establish a trust. Therefore, the only alternative was to have a legal guardian appointed in order to handle her assets in the future.

Each state has laws designating which individuals may make health care decisions for a person who lacks decision making capacity and the order of priority among those individuals, in the absence of advance planning documents. In the worst possible scenario, this means that health care decisions could be made by an individual with whom the cognitively impaired elder has had no contact for many years and who may not understand the elder person's values and desires. Too, individuals who are designated by law to make such decisions may do so based on their own feelings, rather than the wishes of the elderly patient. As an example, an adult child who has been estranged from his/her parents for many years may choose to maintain the parents on life-sustaining equipment, which the parents would not have wanted, out of a sense of guilt and an inability to address or resolve the conflicts that had plagued their relationship.

References

- AARP (2006) History and mission. Retrieved February 23, 2006, from http://www.aarp.org/about_aarp/aarp_overview/a2003-01-13-aarphistory.html
- American Bar Association Commission on Law and Aging, Hurme SB (2004) Monitoring following guardianship proceedings. Retrieved July 16, 2004, from <http://www.abanet.org/aging/guardian5.pdf>
- American Bar Association Commission on Law and Aging, Hurme SB (2004a) Conduct and findings of guardianship proceedings. Retrieved July 16, 2004, from <http://www.abanet.org/aging/guardian6.pdf>
- American Bar Association Commission on Law and Aging, Hurme SB (2004b) Initiation of guardianship proceedings. Retrieved July 16, 2004, from <http://www.abanet.org/aging/guardian2.pdf>
- American Bar Association Commission on Law and Aging, Hurme SB (2005) Notice in guardianship proceedings. Retrieved September 20, 2006, from <http://www.abanet.org/aging/docs/Chart-Notice-12-05.pdf>
- American Bar Association Commission on Law and Aging, Hurme SB (2006) Representation and investigation in guardianship proceedings. Retrieved September 25, 2006, from <http://www.abanet.org/aging/docs/Chart-Representation-12-05.pdf>
- American Bar Association Commission on Legal Problems of the Elderly (2002) Appendix 1: Health care power of attorney and combined advance directive legislation. Retrieved July 16, 2004, <http://www.abanet.org/ftp/pub/aging/hcpacht02.pdf>
- Barnett TJ (1992) Living wills and more, Wiley, New York
- CCH (2006) Financial planning toolkit. Retrieved February 23, 2006. <http://www.finance.cch.com/financetoc.asp>
- Center for Social Gerontology (2004) Guardianship and alternatives. Retrieved July 2004, from <http://www.tcsg.org>
- Doukas DJ, Reichel W (1993) Planning for uncertainty: a guide to living wills and other advance directives for health care, The Johns Hopkins University Press, Baltimore, MD, pp27, 60, 118–119
- Guardianship Over the Elderly (2003) Security provided or freedoms denied?: Hearing before the Special Committee on Aging, Senate, 108th Cong., 1st Sess., 2003, pp43–46, 78, 97–99,109, 110, 112–116
- Johns AF (2004) Older clients with diminishing capacity and their advance directives. *Real Property, Probate Trust J* 39:107–134
- Krohm C, Summers S (2002) Advance health care directives: a handbook for professionals, American Bar Association, Chicago, IL, pp 7, 10–12, 117, 136–138
- Lynn J (2003) Why I don't have a living will. *The Law of Bioethics: Individual Autonomy and Social Regulation*. Thomson West, St. Paul, MN, pp318, 321
- NAMI (n.d.a) NAMI's position on psychiatric advance directives. Retrieved July 26, 2004, from http://www.nami.org/Template.cfm?Section=Issue_Spotlights&template=/ContentManagement/ContentDisplay.cfm&ContentID=8382
- NAMI (n.d.b) Psychiatric advance directives: an overview. Retrieved July 26, 2004, from http://www.nami.org/Template.cfm?Section=Issue_Spotlights&template=/ContentManagement/ContentDisplay.cfm&ContentID=8381
- National Guardianship Association (n.d.a) Guardianship/conservatorship—an overview. Retrieved July 16, 2004, from <http://nga.affiniscape.com/associations/2543/files/guard-conserv.pdf>
- National Guardianship Association (n.d.b) Rights of an individual under guardianship. Retrieved July 16, 2004, from <http://nga.affiniscape.com/associations/2543/files/rightsofward.pdf>
- National Mental Health Association (n.d.a) Psychiatric advance directives: issue summary. Retrieved July 29, 2004, from <http://www.nmha.org/position/advancedirectives/PADSummary.pdf>
- National Mental Health Association (n.d.b) Psychiatric advance directives toolkit. Retrieved July 26, 2004, from <http://www.nmha.org/toolkit/advancedirectives/index.cfm>
- Ohio Department of Aging, Ohio Elder Abuse Task Force Final Report, Published January 2005, <http://www.goldenbuckeye.com/eatffinal.pdf>
- Sabatino CP (2003) De-Balkanizing state advance directive law. BIFOCAL, 25. Retrieved July 16, 2004, from <http://www.abanet.org/aging/bifocal251.pdf>
- Sabatino CP (n.d.) 10 legal myths about advance medical directives. Retrieved July 16, 2004, from <http://www.abanet.org/aging/myths.html>
- Smith GP II (1996) Legal and healthcare ethics for the elderly. Taylor & Francis, Washington, DC, pp40, 59, 60
- Summers SK (1996) Guardianship and conservatorship. American Bar Association Senior Lawyers Division, Chicago, IL, pp6, 10, 30, 46, 58, 59, 64, 105, 110
- United States Government Accountability Office (2004) Guardianships: collaboration needed to protect incapacitated elderly people. Retrieved July 23, 2004, from <http://www.gao.gov/new.items/d04655.pdf>



5 The Participation of Cognitively Impaired Elderly in Research

Sana Loue

Introduction

A significant body of literature has developed that addresses the various ethical issues arising in the context of the recruitment and enrollment into research protocols of cognitively impaired individuals, institutionalized individuals, and elderly persons. Much of this discourse has taken place between professionals in the medical, public health, and legal arenas. This article is not intended to debate the various points raised in these discussions. Rather, it is intended as a guide to the relevant issues for individuals involved in the professional care and caregiving of cognitively impaired elderly individuals, whether residing in their communities or in institutions, who may be called upon by their elderly patients, family members, or friends to assist in decisionmaking regarding their participation in research.

The need for such guidance is critical and growing. Estimates suggest that 4 million people in the United States currently have Alzheimer's disease and, among those aged 85 and older, the prevalence of the disorder approaches 50% (Evans et al. 1989; Markesbery 1998). It has been estimated that as many as 5 million individuals will demonstrate evidence of dementia by the year 2040, when the Baby Boomers reach "old age" (Manning 1993) and that by the year 2050, as many as 13.2 million will be affected by Alzheimer's disease (Hebert et al. 2003). This means that 1 out of every 45 Americans will have Alzheimer's disease (Brookmeyer et al. 1998).

Yet additional individuals will experience a lesser level of cognitive impairment due to various other causes, including mental illness, stroke, adverse drug interactions, acute infections (Buckwalter et al. 1999), mental retardation (American Association in Mental Retardation 2004), and/or malnutrition (Goodwin et al. 1983; Manders et al. 2004). In the absence of a formal assessment, these individuals may not be recognized by their primary care physicians as experiencing any level of cognitive impairment. For instance, a study of 3954 apparently relatively healthy primary care patients over the age of 60 found that 10.5% had mild impairment and 5.2% had moderate to severe impairment (Callahan et al. 1995). Less than one-quarter of those found to have severe impairment had been recorded by their physicians as having dementia. In yet another study of 2212 community-dwelling African American residents aged 65 and older in Indianapolis, it was found that almost one-quarter (23.4%) experienced some level of cognitive impairment (Unverzagt et al. 2001).

Many such individuals may eventually be forced to reside in a nursing home or other residential facility, despite their preference for other living arrangements. The National Alzheimer's Association, which has traditionally supported home- and community-based care to the extent possible, has noted

For many, perhaps most people with Alzheimer's disease, the time will come when it is no longer possible to stay at home—because there is no caregiver (at least 20% of people with Alzheimer's disease live alone); because they need more care than their family can provide; or because their caregiver becomes too frail or ill to continue (Alzheimer's Association 1997a, b: 11).

In 1990, 1% of those aged 65–74 lived in a nursing home, while among those aged 85 and older, one out of every four persons did (United States Census Bureau 2001b). The 2000 census indicates that 4.5% of all individuals aged 65 and older are residing in nursing homes (United States Census Bureau 2001a). Researchers have estimated that, at any given time, approximately 5% of the older population is confined to institutions (Himes et al. 2000).

These data indicate that a significant proportion of the aging population may be suffering from varying levels of cognitive impairment that have remained largely undetected, even by health care providers. A careful

questioning is critical in order to identify patients who may require referral for further assessment and who may need support in deciding whether or not to participate in research.

Conducting research with elderly persons suffering from cognitive impairment is critical if we are to improve our understanding of the causes of their cognitive impairments, our ability to assess individuals' capabilities, and our ability to develop and implement more effective and supportive interventions. Yet past history demonstrates the vulnerability of cognitively impaired individuals and institutionalized persons to abuse in research (Advisory Committee on Human Radiation Experiments 1996; Bein 1991; Garnett 1996; Lubasch 1982; Rothman 1991; *Scott v. Casey* 1983; *Valenti v. Prudden* 1977). An outright prohibition against the participation of cognitively impaired elderly in research would shield them from the potential for such abuse, but would also result in a loss of their individual autonomy, possibly foster their societal isolation and stigmatization. Such a prohibition would also deprive future generations of important scientific knowledge critical to the amelioration and/or prevention of disease and the improvement of care. Consequently, elderly individuals may face the twin dangers of exploitation and overprotection; our challenge is to foster such research while simultaneously protecting vulnerable elderly individuals from potential exploitation and abuse.

The Requirement of Informed Consent

Ethically and legally, researchers are required to obtain the informed consent of an individual in order to enroll an individual into a study. This ethical requirement was derived from several international documents, including the Nuremberg Code and the Helsinki Declarations, and has been integrated into US law by federal regulations. These federal regulations state that "no investigator may involve a human being as a subject in research . . . unless the investigator has obtained the legally effective informed consent of the subject or the subject's legally authorized representative" (Code of Federal Regulations 2005). The term "legally authorized representative" is defined in the regulations as "an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research" (Code of Federal Regulations 2005). A number of states have implemented state regulations or statutes which govern in addition to the federal laws and which should be consulted to verify if an individual has legal status to make a decision on behalf of another individual. For instance, a blood or marital relationship may not be sufficient under law to authorize an individual to serve as a legal representative, as is the case in New York State.

The federal regulations, however, do not provide specific guidance to researchers who wish to conduct studies with cognitively impaired individuals. A number of organizations have developed guidelines, including the Alzheimer's Association (Alzheimer's Association 1997a, b), the American College of Physicians (American College of Physicians 1989), the Clinical Center of the National Institutes of Health (National Institutes of Health Clinical Center 1987), the Council of International Organizations of Medical Sciences in collaboration with the World Health Organization (Council for International Organizations of Medical Sciences 2001), the Council of Europe (Council of Europe 1997), and the British Medical Research Council (Medical Research Council Working Party on Research on the Mentally Incapacitated 1991).

Valid informed consent requires that four elements be present: (1) the individual from whom consent is to be obtained must be given the information necessary to make a decision; (2) the individual must understand the information; (3) the prospective participant must have the capacity to consent; and (4) the consent of the individual to participate must be voluntary (Faden and Beauchamp 1986; Meisel et al. 1977). It cannot be emphasized enough that informed consent is a process that continues from the time of recruitment and enrollment throughout the study; it is not and should not be construed as the mere presentation to and signing of a document by the prospective research participant.

Enhanced protections during this informed consent process may be ethically required for cognitively impaired elderly individuals who may become research participants, due to their potential vulnerability. Vulnerable participants are those individuals with "insufficient power, prowess, intelligence, resources, strength, or other needed attributes to protect their own interests through negotiations for informed consent" (Levine 1988: 72). This could encompass, among others, elderly individuals suffering from varying levels of cognitive impairment,

dementia, mental illness, and mental retardation. These additional protections are discussed below in the context of presenting information, ensuring understanding, assessing capacity to consent, and voluntariness. Additional considerations critical to informed consent are also addressed. These include confidentiality, elder abuse and neglect, and balancing the risks and benefits of participation in a research study.

Presenting Information

As an example of a situation in which inadequate information was provided to prospective research participants, consider the following statement that appeared in an informed consent form presented in conjunction with an 8-week, double-blind, crossover study of the effectiveness of imipramine compared to placebo on depression. This study was conducted from 1959 to 1960, prior to the implementation of federal regulations governing research with human participants.

The kind of trouble you have been telling me about often responds quite well to medicine. We now have two different medicines available that we know help many people with difficulty like yours. However, some people do better with one and other people do better with the other medicine. The best way to find out which of the two medicines is best for you personally is to try them both. So we have set up a treatment program that will give you the opportunity to do just that. You will be able to take each medicine for 4 weeks. At the end of the 8 weeks, if necessary, you may continue to take whatever medicine works best for you (Park et al. 1967: 350; Uhlenhuth and Park 1964: 103).

The defects in the information presented, if judged against today's standards, are glaring:

- Participants were not advised that they were to participate in research, but were led to believe that this was clinical treatment for their depression.
- Individuals were led to believe that the substances to be administered were both medicines that had been shown to be effective. In fact, one was a placebo with no therapeutic value and the other was a new medication whose effectiveness and efficacy had not yet been assessed.

Federal regulations now require that the following information be provided to all research participants during the informed consent process: (1) a statement that the study involves research, an explanation of the purposes of the research, the expected duration of the subject's participation, a description of the procedures required for participation, and the identification of any procedures which are experimental; (2) a description of any reasonably foreseeable risks or discomforts to the research participant; (3) a description of any benefits from the research that may be reasonably expected for the research participant or others; (4) a disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the research participant; (5) a statement describing the extent to which confidentiality of records identifying the research participant will be maintained; and (6) for research involving more than minimal risk, an explanation as to whether any compensation or any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained; (7) an explanation of whom to contact for answers to pertinent questions about the research and the rights of research participants, and whom to contact in the event of a research-related injury to the research participant; and (8) a statement that participation is voluntary, that a refusal to participate will not involve any penalty or loss of benefits to which the research participant is otherwise entitled, and the participant may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled (Code of Federal Regulations 2005).

In addition to these mandated disclosures, federal regulations indicate that the following information may be provided to research participants where appropriate: (1) a statement that the particular treatment or procedure may involve risks to the research participant (or to the embryo or fetus, if the participant is or may become pregnant) which are currently unforeseeable; (2) anticipated circumstances under which the participation of a research participant may be terminated by the investigator without regard to the participant's consent; (3) any additional costs to the subject that may result from participation in the research; (4) the consequences of a participant's decision to withdraw from the research and procedures for orderly termination of participation by

the participant; (5) a statement that significant new findings developed during the course of the research, which may relate to the participant's willingness to continue participation will be provided to the subject; and (6) the approximate number of participants involved in the study (Code of Federal Regulations 2005). As an example of when such disclosures might be appropriate, consider the following hypothetical scenario.

A woman suffering from the initial stages of Alzheimer's disease is enrolled into a study of an experimental drug that is intended to delay the onset of more severe symptoms. Use of the experimental drug results in an adverse reaction that was not previously seen in research participants or in animal experiments with the drug. An injury to the research participant would not be foreseeable in such circumstances. As the study progresses, this research participant becomes so confused as to be unable to participate meaningfully, and becomes distraught with study procedures to such a great degree that she is actually traumatized by participation. The investigator may choose to terminate the participation of the study participant against her wishes, in order to protect her from further trauma.

Under another scenario, during the course of the study, a pharmaceutical company markets a newly approved drug that will boost memory among those suffering from Alzheimer's disease; the investigators should inform the woman about this product and its availability, even though awareness of its potential usefulness to her may decrease her willingness to continue participation in the study. Although her decision to withdraw would result in a reduction in the number of participants and possibly affect adversely the researcher's ability to draw conclusions from the study, the researcher should still disclose this information to her (Code of Federal Regulations 2005).

Ensuring Understanding

It is critical that individuals understand that they are participating in research and that the procedures that they will undergo may not yield any direct benefit to them. A number of studies have found that many research participants may not understand either that they are participating in research rather than receiving clinical care, or the nature of the procedures that they will undergo in conjunction with their participation (Gray 1975; Fletcher 1973; Howard et al. 1981; Hassar and Weintraub 1976; McCollum and Schwartz 1969; Park et al. 1966; Riecken and Ravich 1982).

The National Bioethics Advisory Commission (2001) has recommended that the informed consent procedure be tailored to the specific abilities of each individual participant to receive and process information. For instance, some elderly patients may have hearing or vision impairments that impede their ability to understand the information in the form in which it might be presented; accommodations must be made for these limitations in order to ensure that potential research participants understand the substance of the information being presented. A number of suggestions have been made to maximize understanding, including the use of a clear and simple presentation format for the information (Bergler et al. 1980), the provision of sufficient time to enable the individual to process the information given to him or her (Morrow et al. 1978), and discussion of the information with the researcher or member of the research team (Williams et al. 1977). The individual may be asked to restate or summarize in his or her own words the information provided in order to confirm that he or she understood. Tailored questions, whether in multiple choice, true–false, or essay format, may be asked of the participant following the presentation of the information, to ascertain whether and how much the prospective participant understood of the information presented (Bonnie 1997; Flanery et al. 1978; Hassar and Weintraub 1976; McCollum and Schwartz 1969; Williams et al. 1977). One commentator has suggested that a family member participate with the cognitively impaired member in the informed consent process to ensure understanding and provide concurrent consent (Bonnie 1997).

Assessing Capacity to Consent

The terms *capacity* and *competence* are often used synonymously, but they actually represent distinct concepts. The term *capacity* is used here to refer to an individual's decisionmaking ability. In contrast, the term *competence*

reflects a legal judgment that an individual has a minimal level of mental, cognitive, or behavioral functioning to perform or assume a specified legal role (Bisbing et al. 1995; Loue 2001). It is important to recognize that being diagnosed with a particular condition is “relevant to, but not determinative of, incapacity for informed consent” (High et al. 1994). For instance, the course of schizophrenia may fluctuate, so that there may be periods of time during which an individual is able to understand and to give legally valid consent. • [Table 1](#) provides a brief

■ **Table 1**

Summary of common causes of diminished decisionmaking capacity in elderly individuals

Cause of diminished capacity	Presenting signs and symptoms
Alzheimer’s disease	Progressive degenerative brain disorder characterized by severe amnesia, lapses of short-term, memory, deficits in language, attention, executive functions, and visuospatial and constructional abilities (Masliah et al. 1993)
Depression	Symptoms include sleep disturbance, loss of appetite, impaired concentration, poor memory, psychomotor retardation, constipation, somatic pain, depressed mood, suicidal ideation (DeLisa and Gans 1993; Lakshmanan et al. 1986); decreased motivation may impede ability to protect own interests, causing reduction in decisionmaking capacity (Elliott 1997)
Frontal lobe dementia	A disorder of unknown cause, also known as frontotemporal dementia; characterized by slow and insidious progression, early loss of personal and social awareness such as neglect of personal hygiene, distractibility, mental rigidity and inflexibility, ritualistic behaviors, incontinence, the repetition of a limited number of words and phrases, the progressive reduction of speech, and echolalia (Usman 1997)
Huntington’s disease	A genetically transmitted neurodegenerative disorder (Bylsma 1997); onset may occur at any age; average duration is 15–17 years; characterized by moderate episodic or semantic memory disturbance, attention dysfunction, and deficits in problem-solving, arithmetic, and visuospatial abilities (Bylsma 1997; Salmon and Bondi 1997)
Lewy body dementia	Characterized by sudden onset and fluctuating level of awareness, frequently with visual and auditory hallucinations (Kennedy 2000); severe deficits in attention, verbal fluency, and visuospatial processing (Hansen et al. 1990)
Schizophrenia	Characterized by delusions, hallucinations, thought disorder, grossly disorganized or catatonic behavior, negative symptoms, social and/or occupational dysfunction (American Psychiatric Association 2000)
Vascular dementia	Also known as multifarct dementia (Roman 1991); earlier age of onset than other forms of dementia, abrupt onset, fluctuating course, nocturnal exacerbation of confusion, limb rigidity, incontinence, and gait abnormality
Wernicke-Korsakoff syndrome	Results from prolonged and heavy consumption of alcohol, characterized by permanent short-term memory impairment, resulting in an inability to remember new information for more than a relatively brief period of time (Oscar-Berman and Evert 1997); may also involve deficits in visuospatial, abstraction, and problem-solving abilities, with appearance of emotional apathy

synopsis of many common causes of incapacity in elderly individuals.

Care providers and caregivers approached by their elderly patient, family member, or friends for advice about participating in research, or by a member of a research team about an elderly person’s enrollment into a research study, will want to ask the following questions: Under what conditions will capacity be assessed? Who will conduct the capacity assessment? How will the assessment be conducted and what specifically will be assessed? How will the accuracy of the assessment be verified?

Under What Conditions Will Capacity Be Assessed?

It is critical that the conditions under which capacity is to be assessed maximize the likelihood that an accurate finding will be achieved. First, it is important that the individual who is to assess capacity be matched

appropriately with the prospective research participant (Kennedy 2000). For instance, an older woman with a history of being abused by her partner as she became increasingly dependent upon him physically for her care may be intimidated by the presence of a male interviewer and may choose to remain mute. Individuals, such as some elderly immigrants, who have been raised in cultures that demand deference and obedience to those endowed with power, authority, or greater social status, may be unwilling to answer some questions honestly, fearing that they will offend the interviewer.

An individual's ability to respond to questions posed or to perform well on a test of cognitive ability may also be impacted by iatrogenic and institutional factors (Kennedy 2000). The elderly individual's ability to concentrate or his or her level of awareness may be affected by his or her medications. Individuals accustomed to the regimentation associated with institutionalization may become confused or frightened with a change in routine; in the absence of careful assessment, signs of that confusion may be mistaken for signs of diminished capacity.

Other conditions may also adversely impact an individual's performance on an assessment of cognitive functioning. These include environmentally induced stress, such as sleep deprivation; recent bereavement, resulting in depression and a decline in functional ability; and fluctuating symptoms of pre-existing mental illness (American Psychiatric Association 2000). Physiological causes, such as fluctuations in the blood sugar of individuals with diabetes, sodium deficiency, and electrolyte imbalances, can also affect cognition.

Who Will Conduct the Capacity Assessment?

It has been suggested by some commentators that the assessment and monitoring of an individual's capacity to consent and to participate in a study is best done by the research team of a study in collaboration with family members (Keyserlingk et al. 1995). Four exceptions to this basic premise have been noted: (1) when project staff do not have the requisite skill to assess or monitor the participant's capacity; (2) when there is a strong danger of conflict of interest; (3) when the individual had previously executed an advance directive for research while he or she still had capacity, but the document requires interpretation; and (4) when the protocol does not have the potential to confer a direct benefit on the participant and it involves more than minimal risk.

How Will the Assessment be Conducted and What Specifically Will be Assessed?

There are many instruments that have been developed to assess capacity. Several of those that are in common use are listed in [Table 2](#), with the following caveat. These instruments will distinguish those individuals who are suffering from severe limitations in cognition and/or memory; they are inadequate to detect more subtle limitations, which will require a more thorough assessment.

In general, it is presumed at the commencement of research studies that a prospective participant has capacity to consent, unless there is *a priori* reason to believe that he or she does not or that the capacity to give consent may be limited in some way. Clearly, if a study focuses on a disorder involving either permanent cognitive impairment, such as mental retardation, progressive impairment, such as Alzheimer's disease, or fluctuating impairment, such as schizophrenia, an assessment of capacity should be conducted at the commencement of participation. Because capacity and decisionmaking ability may vary during the course of the study, depending upon the length of the study and the progression of the disorder or disease, it is also recommended that assessments of capacity and decisionmaking ability be conducted periodically during the course of an individual's participation in research, unless that participation is of very short duration.

How Will the Accuracy of the Assessment be Verified?

It has been suggested that a determination of capacity be verified through reliance on second opinions or the services of individuals who are consent specialists (Bonnie 1997).

■ **Table 2**

Common instruments used to assess capacity and/or memory

Instrument	Purpose	Design
Mini-Mental Status Examination (MMSE)	Measures cognitive capacity, specifically, orientation, ability to remember, attention, ability to calculate, ability to understand language and symbols (Folstein et al. 1975; Petersen et al. 2001)	Questions relate to orientation to time and place, requests to remember specified objects, to repeat designated phrases, and to name specified objects; impairment measured on continuum; lower scores indicate increased level of impairment and decreased capacity
Standardized Mini-Mental Status Examination (SMMSE)	Like MMSE	Standardizes time allotted to each question and answer, reducing length of test (Molloy et al. 1991)
Dementia Scale	Assesses cognitive capacity	Utilizes 10 questions related to orientation to time and place; lower score indicates greater impairment and lesser capacity (Kahn et al. 1960); usefulness with marginalized and unacculturated populations questionable
Clock Drawing Test	Assesses cognitive capacity	A 5-min test that asks the respondent to draw a clock with all the numbers on its face and state the time as it is drawn; awards points for the inclusion of all 12 numbers, the correct placement of numbers, the inclusion of two hands, and for correctly stating the time (Stahelin et al. 1997)
7-min Neurocognitive Screening Battery	Assesses memory; distinguishes on a preliminary basis between individuals experiencing cognitive deficits as a result of dementing disorders and those experiencing cognitive changes due to the normal aging process (Solomon et al. 1998)	Addresses orientation aphasia, clock drawing, and free and cued recall memory response (Solomon et al. 1998)

Voluntariness

The life situation of many elderly persons may affect their ability to consent or to refuse consent to participate in research. Some elderly individuals may be dependent on others for their physical care, for attention to their personal needs, or for their medical care. They may fear that if they refuse to participate in a particular research study, they will suffer the withdrawal of such assistance, a diminution in the quality of this assistance, or complete abandonment. This may be of particular concern to individuals living in institutions, such as nursing homes or mental hospitals (Annas and Glantz 1997). Individuals may also be concerned that they will disappoint their caregiver or care provider if they refuse to participate (Sachs and Cassel 1989). Some individuals may also believe that they would not have been offered the possibility of participation in a study unless the researcher believed that their participation would yield some clinical benefit to them personally. They may believe this despite all assertions by the research team that they may not receive any personal benefit from their participation and only future patients will derive any benefit from the new-found knowledge gained through the study. This misconception is known as the “therapeutic misconception” (Grisso and Appelbaum 1998).

Other Considerations Relating to Informed Consent

Confidentiality of the Data

The level of confidentiality protection of the information that is disclosed to the researcher may be of concern for a number of reasons. If there are inadequate protections, it may be advisable to refrain from participation. First,

confidentiality may be difficult to maintain if interviews or other procedures are conducted in the context of an institutional residence, such as a nursing home, due to the physical layout of the institution, a scarcity of private space, and the possibility that the participant may have impaired hearing ability, thereby requiring that the researcher speak at a level that is audible to others (Cassel 1985, 1988). The elderly individual may not want other individuals to hear the responses for any number of reasons.

Depending upon the nature of the study, attempts to access the study data could be made through the legal system. For instance, assume that a study is examining resilience and social support among the elderly. The researchers know through their interviews with a participant that he has been abusing alcohol. He is the driver in an accident in which the passengers of the other car are seriously injured. The insurance company for the injured passengers obtains a subpoena of the study records for this participant, claiming that the research records are relevant to the driver's negligence. It is critical that the investigators apply prior to the collection of data for a federal certificate of confidentiality to protect the data from subpoena if they believe that similar situations might arise, or if they are collecting data that may be of some interest to law enforcement or lawyers (National Institutes of Health 2005).

Elder Abuse and Neglect

As of March 1993, all states and territories, with the exception of Puerto Rico, had enacted laws to address elder abuse in domestic and institutional settings (Tatara 1995). (Some states also have legislation to protect disabled adults regardless of their age.) Accordingly, if abuse of an elderly research participant is suspected, the researcher may be obligated by state law to report that abuse, even if the participant indicates that he or she does not want the information provided to the designated authority. Essentially, the mandated reporting requirement will trump the participant's right to have this information about him or her kept confidential. Whether the suspected abuse must be reported will depend on whether the particular situation is encompassed in the state's definition of abuse, whether the elderly individual is within the age group specified in the state's definition of "elderly," whether the elderly person meets the definition of state residence or a physical presence requirement set forth in the governing state statute, whether the researcher is in a category of persons that is mandated by the state law to report elder abuse, and whether the researcher has obtained a certificate of confidentiality to exempt him or her from the reporting requirement (Loue 2001).

Assessing and Balancing Risks and Benefits

A decision about whether a cognitively impaired elder should participate in a research protocol requires that the decision-maker balance the risks and benefits to the individual of his or her participation. A balancing of risks and benefits must be done by the researcher proposing the study prior to its initiation and must also be conducted by the institutional review board (IRB) of the researcher's institution in its initial and continuing reviews of the research protocol. [IRBs are established by institutions to review research protocols as mandated by federal regulations for the receipt of such funding (Code of Federal Regulations 2005).] However, the assessment of risks and benefits by the researcher and the IRB focus on an examination of the risks and benefits to the class of persons to be enrolled into the study and not on the benefits or risks that an individual participant may experience. Consequently, it is very important that the elderly individual, his or her surrogate decision-maker, and/or the individual advising the elderly person work with the elderly person to determine the risks and benefits of participation to that specific individual.

Commentators have identified four categories into which research protocols may be classified: (1) research in which there is the potential for a direct therapeutic benefit to the participant and minimal risk is involved; (2) research in which the participant may obtain some direct therapeutic benefit, but more than minimal risk is involved; (3) research in which there is no expected benefit for the individual participating, but there is no more than minimal risk; and (4) research in which there is no expected therapeutic benefit to the participant and there

is more than minimal risk (Kapp 1998; LeBlang and Kirchner 1996). “Minimal risk” is often interpreted to mean that the risks of participation are no greater than those that would be experienced in the everyday course of living (Levine 1988).

Direct benefits may include short- or long-term improvement in the individual’s condition, an improvement in the individual’s symptoms, and the slowing of the degenerative process (Keyserlingk et al. 1995). Indirect benefits may include enhanced opportunities for social interaction, increased attention from health and ancillary health professionals, and a feeling of contributing in a way that may help others. Examples of risks include the physiological effects of an experimental drug or procedure and increased levels of anxiety associated with study questions or procedures (Dresser 2001).

Research suggests that even when risks of study participation are divulged to prospective participants, individuals may have difficulty comprehending the risks. In one clinical trial of a drug, respondents were found to be well informed about the study design and general risks of participation, but 39% were unable to enumerate specific minor side effects of the drug and 64% were unable to identify the serious risks of the medication that had been divulged to them (Howard et al. 1981). In yet another study, few of the respondents recognized the possibility of unknown risk, meaning that there could be risks that had not been anticipated prior to the initiation of the study (Gray 1975).

There is no formula that will dictate how the benefits and risks of a particular individual’s participation are to be weighed against each other. In fact, there is no consensus among researchers or ethicists as to the level of risk or benefit that must be present for a surrogate decision-maker to be able to consent to research participation by a cognitively impaired individual (Dresser 2001). It is critical that the elderly individual, together with his or her surrogate and/or others, carefully consider how the study procedures will affect their individual situation. [▶ Table 3](#) lists a number of questions that may be posed that will be helpful in this analysis.

■ Table 3

Consideration for participation in research by cognitively impaired elderly persons

How much time will participation require? At what intervals? Am I physically able to spend this much time participating?
If I am to spend long periods of time at the study site, what provisions will be made to provide me with meals or to administer other medications that I need?
What procedures are involved in the study? How do I usually react to such procedures (blood test, etc.)? Has my response changed?
Do I have transportation to go back and forth to the study site?
Does participation require a change in medications? Invasive procedures, such as a lumbar puncture? How do I feel about such procedures?
Will the study investigators provide their findings to my health care provider(s) to supplement the care that I am receiving?
To what extent will the information that I provide be kept confidential? For instance, what if a study researcher thinks I should not drive. Is he going to report it to the license bureau?
To what extent will the study staff share information with my caregiver(s) if I want them to do so?
If I am provided with new medication during the course of the study and it is found to be beneficial, will I be provided with the medication after the study ends?
Do any study procedures conflict with my religious principles or spiritual beliefs; for example, am I going to be asked to consent to an autopsy, which is prohibited by my religion?

Mechanisms for Expressing Choice During Incapacity

Advance Directives for Research

Because of the slow and progressive course of many dementias, and the intermittent nature of various other disorders that may impact decisionmaking ability, such as schizophrenia, some commentators have suggested

that individuals should be able to indicate in advance their desire to participate in research (Levine 1988). For instance, an individual at the beginning stages of Alzheimer's disease may strongly believe that he or she would like to participate in research if the opportunity were to arise, but fears that he or she will be unable to give consent at a future date, when the illness has progressed. Accordingly, the individual might want to express this intent at a time when he or she is still able to do so, when legally that expression will be recognized as valid.

One mechanism that has been suggested is an advance directive for research. Similar to an advance directive for health care, such a document would allow the individual to make his or her wishes known at a time when the individual retains decisionmaking capacity. Alternatively, the individual might execute a durable power of attorney for health care and specify that his or her designated agent should have the legal authority to decide for him or her whether participation in a particular research study would be advisable and to provide or withhold consent accordingly.

This type of advance decisionmaking may be an option, depending upon the residence of the elderly individual; not all states provide for such a document or recognize an agent as having the authority to make research-related decisions. Even where this possibility exists, many elderly individuals may be unaware of the mechanism. Even in the context of health care, it appears that only a minority of elderly patients execute durable powers of attorney for health care, often due to lack of knowledge about the mechanism or the erroneous assumption that a relative will automatically be able to make health care decisions for them if they are unable to do so (Cohen-Mansfield et al. 1991).

There are other difficulties associated with an advance directive for research even if the individual state permits this mechanism. Because the informed consent process is supposed to be ongoing throughout the course of the study, an individual who consents to participate before knowing what a study is about is not really giving *informed* consent.

Questions also arise about the current validity of the prior expression to participate in research because changes in the individual's situation may have occurred during the intervening period of time. For instance, an individual may have indicated while he or she had capacity to do so an intent and desire to participate in research. However, a number of years have passed and the elderly individual's mental abilities and awareness of his or her surroundings have declined. Some ethicists, distinguishing between the "then-person," the precursor to the person who now lacks capacity, and the "now-person," have argued that, as the individual's capacity decreases, so should the weight to be given to his or her previously expressed wishes in an advance directive decrease (Brock and Buchanan 1989; Dresser 1992). This perspective results in the incongruous result whereby the greatest weight is given to the severely demented now-self's needs, who has the least psychological continuity with his or her former competent self (Klepper and Roty 1999). Others have emphasized the concept of "precedent autonomy" and have argued that past decisions of the competent then-self must be respected even if they are not consistent with the wishes of the cognitively impaired now-self (Dworkin 1994). Still others have argued for the compassionate application of the principle of precedent autonomy, which would permit the implementation of previously expressed wishes as long as doing so does not result in discomfort to the now-self (Post 1995).

Surrogate Consent

Even in the absence of a legally executed document, such as an advance directive for research, some have suggested that elderly individuals who lack capacity to consent should be able to participate in research through the consent of a surrogate. Federal regulations permit a "legally authorized representative" to provide consent in some circumstances where the prospective participant is unable to do so (Code of Federal Regulations 2005). However, some states may place severe restrictions on the ability of cognitively impaired individuals to participate in research, on the ability of a legally authorized representative to consent to an individual's participation in research, and/or may require judicial approval for such participation. [▶ Table 4](#) provides a partial listing of the states that have such restrictions, as well as the citation to these statutory provisions and relevant court decisions.

A question arises as to which individual(s) are best suited to be appointed as the surrogate decision-makers. The National Alliance for the Mentally Ill (NAMI) has proposed that family members are the most appropriate

■ Table 4

Examples of state law provisions restricting ability of cognitively impaired individuals and/or their surrogate decision-makers to consent to participation in research

State	Limitation	Provision
California	Conservator may consent to participation "only for medical experiments related to maintaining or improving the health of the subject or related to obtaining information about the pathological condition of the subject"	California Health and Safety Code § 24175(e) (West 1992)
Connecticut	Guardian may consent to participation in any biomedical or behavioral medical procedure or participation in any behavioral experiment "if it is intended to preserve the life or prevent serious impairment of the physical health of the ward or it is intended to assist the ward to regain his abilities" and has been approved for that person by the court	Conn. Gen. Stat. Ann. § 45a-677(e) (West Supp. 1997)
Delaware	Prohibits approaching residents of state mental hospitals for participation in pharmaceutical research if individual is "incapable of voluntary consent to care or treatment"; prohibits specified classes of state mental hospital residents from participating in pharmaceutical research, regardless of capacity	Del. Code Ann. Tit. 16, §§ 5174, 5175 (1995)
Illinois	Parent or guardian may not consent to ward's participation in any "unusual, hazardous, or experimental services" without approval by the court and determination that such services are in the "best interests" of the ward	§ 405 Ill. Comp. Stat. Ann. 5/2-110 (West 1993)
Massachusetts	Prohibits research on patients in mental facilities if the research will not provide direct, therapeutic benefit; prohibits research on patients with mental disabilities where the risk is greater than minimal and exceeds the benefit to the participant	Mass. Regs. Code tit. 104 § 13.01-.05 (1995)
Michigan	Experimental psychosurgery cannot be performed on a mentally incompetent person even if the surrogate decision-maker consents	Kaimowitz v. Michigan Department of Mental Health, in Disability Law Reporter, 1, 147 (1976); U.S. Law Week, 42, 2063 (Circuit Court, Wayne County, Michigan, 1973)
Minnesota	Guardian or conservator prohibited from giving consent to experimental treatment of any kind unless the procedure is first approved by the court, which will determine if it is in the "best interest" of the ward	Minn. Stat. Ann. § 524.5-313(c)(4) (2003)
Missouri	Prohibits state mental health patients from being "the subject of experimental research," with stated exceptions; prohibits the conduct of biomedical or pharmacological research on any individual with mental disabilities unless the research will provide direct therapeutic benefit	Mo. Stat. Ann. § 630.115(8) (West Supp. 1997)
New Hampshire	The probate court may authorize the guardian to consent to experimental treatment only after ensuring that the treatment is in the ward's "best interest"	N.H. Rev. Stat. Ann. § 464-A:25(l)(c)-(e) (1995)

■ **Table 4 (continued)**

State	Limitation	Provision
New York	Residents in a facility operated by NY State or licensed by the Office of Mental Health who lack decisionmaking capacity may not be participants in any non-federally funded non-therapeutic research that poses greater than minimal risk unless the individual, prior to the onset of his or her incapacity, gave specific consent or designated an appropriate surrogate from whom consent can be obtained	T.D. v. New York State Office of Mental Health, 650 N.Y.S.2d 173 (N.Y. App. Div. 1996), appeal dismissed, 680 N.E.2d 617 (N.Y. 1997), leave to appeal granted 684 N.E.2d 281 (N.Y. 1997), appeal dismissed, 1997 WL 785461 (NY., Dec. 22, 1997)

surrogates in the research context (Flynn 1997). Many IRBs allow family members or friends to give consent (LeBlang and Kirchner 1996). However, some IRBs interpret the phrase “legally authorized representative” in the federal regulations narrowly and require that the surrogate be a court-appointed guardian, a designated health care agent under a written durable power of attorney for health care, a health care surrogate as defined by the relevant state law, or a combination of these individuals (LeBlang and Kirchner 1996). At least one commentator has argued that judicial approval must be obtained any time an individual is to be involved in research if that individual is unable to consent for himself or herself (Bein 1991).

A number of commentators have pointed out the dangers to the elderly individual of having decisions made by a surrogate, whether appointed through the execution of a document or not. First, family members may be inappropriate due to their own lack of capacity, unavailability, or inattention to the needs of the cognitively impaired individual (High et al. 1994). Second, the surrogate may act in his or her own interest, rather than that of the elderly individual. This is most likely to occur if (1) the surrogate fears that the elderly individual will develop dementia and enrolls the individual in research even if it is not to the benefit of the elderly individual or (2) the surrogate serves in a caregiver role and the participation of the elderly individual in research will provide the caregiver–surrogate with a period of respite, regardless of the risks or benefits to the elderly individual of participation (Sachs 1994). Accordingly, it has been suggested that an appropriate surrogate be an individual who (1) is chosen, known, and trusted by the individual; (2) participates with the cognitively impaired individual in the informed consent process; (3) is familiar with the individual’s medical and psychiatric history; (4) in situations in which the elderly individual has a mental illness, is familiar with the prodromal signs and symptoms indicative of a relapse; (5) is informed about and is willing to assume the responsibilities of a surrogate decision-maker; (6) is willing to overrule the individual’s previously expressed desire to participate in research if the participation could adversely affect the individual; and (7) is willing and able to ensure appropriate medical and/or psychiatric follow-up care if needed (Backlar 1998).

Assuming that a surrogate, whether legally appointed or not, is able to decide for the elderly individual who lacks capacity to decide for himself or herself, there remains the question of how the surrogate should make that determination. Two processes have been suggested: the best interest test and the substituted judgment test. The best interest test requires an assessment of what is in the individual’s best interest at the time that the decision by the surrogate is to be made. This perspective allows a surrogate to more easily disregard any previously expressed desire or intent of the elderly individual because what was once expressed may no longer be in his or her best interest, as determined by the surrogate. The substituted judgment test requires that the surrogate decide the issue of research participation in a manner consistent with what the individual would have chosen for himself or herself if he or she had remained able to do so. This perspective allows the surrogate to preserve to a greater degree the psychological continuity between the once-capable then-self and the now-self. In situations in which an IRB permits reliance on the substituted judgment test, the IRB may require in addition to the surrogate’s consent, the assent of the elderly individual to participate, meaning that, to the best of their ability, they must indicate some preference, although that indication does not rise to the level of legal consent (cf. Sachs et al. 1994).

Conclusion

Each individual approached for his or her participation in research must carefully consider whether such participation is advisable in view of his or her own circumstances. Care providers and caregivers may be called upon to participate in and lend their guidance to this decisionmaking process. In order to make this decision, prospective research participants and their advisors must be equipped with as much knowledge as possible about the research, the expectations of the elderly participant engaging in such research, and the likely impact of the participation on the elderly individual. The risks and benefits to the elderly participant must be clearly identified and carefully considered and weighed. Researchers must be cognizant of and compliant with any state laws that may limit the ability of surrogate decision-makers to consent to research participation on behalf of the elderly individual. The participation in research of cognitively impaired elderly adults is critical if we are to understand the underlying mechanisms of diseases that plague elderly persons and discover effective treatments to prevent such diseases or ameliorate their symptoms. However, it is mandatory that we also protect those individuals who, while assisting in this endeavor through their research participation, are in need of additional protections.

References

- Advisory Committee on Human Radiation Experiments (1996) Final report. The Committee, Washington, DC
- Alzheimer's Association (1997a) National public policy program to conquer Alzheimer's disease. Alzheimer's Association, Chicago, IL
- Alzheimer's Association (1997b) Position statement: ethical issues in dementia research. Alzheimer's Association, Chicago, IL
- American Association on Mental Retardation (2004) Fact sheet: aging older adults and their aging caregivers. Available at <http://www.aamr.org/Policies> (last accessed November 10, 2004)
- American College of Physicians (1989) Cognitively impaired subjects. *Ann Intern Med* 11(10):843–848
- American Psychiatric Association (2000) Diagnostic and statistical manual of mental disorders, 4th edn (revised). American Psychiatric Association, Washington, DC
- Annas GJ, Glantz LH (1997) Informed consent to research on institutionalized mentally disabled persons: the dual problems of incapacity and voluntariness. In: Shamoo AE (ed) *Ethics in neurobiological research with human subjects: the Baltimore conference on ethics*. Gordon & Breach, Amsterdam, pp. 55–79
- Backlar P (1998) Anticipatory planning for research participants with psychotic disorders like schizophrenia. *Psychol Public Policy Law* 4:829–848
- Bein PM (1991) Surrogate consent and the incompetent experimental subject. *Food Drug Cosmetic Law J* 46(5):739–771
- Bergler JH, Pennington AC, Metcalfe M, Freis ED (1980) Informed consent: how much does the patient understand? *Clin Pharmacol Ther* 27:435–440
- Bisbing S, McMenamin J, Granville R (1995) Competency, capacity, and immunity. In: ACLM Textbook Committee (ed) *Legal medicine*, 3rd ed. Mosby-Year Book, St. Louis, Missouri, pp. 27–45
- Bonnie RJ (1997) Research with cognitively impaired subjects: unfinished business in the regulation of human research. *Arch Gen Psychiatry* 54(2):105–111
- Brock D, Buchanan A (1989) *Deciding for others*. Cambridge University Press, Cambridge
- Brookmeyer R, Gray S, Kawas C (1998) Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health* 88:1337–1342
- Buckwalter KC, Stolley JM, Farran CJ (1999) Managing cognitive impairment in the elderly: conceptual, intervention and methodological issues. *Online J Knowledge Synth Nursing* 6(10).
- Bylsma FW (1997) Huntington's disease. In: Nussbaum PD (ed) *Handbook of neuropsychology and aging*. Plenum Press, New York, pp. 245–259
- Callahan CM, Hendrie HC, Tierney WM (1995) Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med* 122(6):422–429
- Cassel C (1985) Research in nursing homes: ethical issues. *J Am Geriatr Soc* 33:795–799
- Cassel C (1988) Ethical issues in the conduct of research in long term care. *Gerontologist* 28:90–96
- Code of Federal Regulations (2005) Title 45, §§ 46.101, 46.102(c), 46.111(a)(4), 46.116.
- Cohen-Mansfield J, Droge JA, Billing N (1991) The utilization of the durable power of attorney for health care among hospitalized elderly patients. *J Am Geriatr Soc* 39:1174–1178
- Council of Europe (1997) Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: convention on human rights and biomedicine. Available at <http://conventions.coe.int/Treaty/EN/Treaties/html/164.htm> (last accessed March 18, 2005)
- Council for International Organizations of Medical Sciences, World Health Organization. (2001) *International ethical guidelines for biomedical research involving human subjects*. Geneva, Switzerland
- De Lisa J, Gans B (1993) *Rehabilitation medicine: principles and practice*, 2nd ed. J.B. Lippincott, Geneva, Switzerland
- Dresser RS (1992) *Autonomy revisited: the limits of anticipatory choices*. In: Binstock RH, Post SG, Whitehouse PJ (eds) *Ethics, values, and policy choices*. Johns Hopkins University Press, Baltimore, Maryland, pp. 71–85

- Dresser R (2001) Dementia research: ethics and policy for the twenty-first century. *Georgia Law Rev* 35:661–690
- Dworkin R (1994) *Life's dominion: an argument against abortion, euthanasia, and individual freedom*. Vintage, New York
- Elliott C (1997) Caring about risks: are severely depressed patients competent to consent to research? *Arch Gen Psychiatry* 54:113–116
- Evans DA, Funkenstein H, Albert MS, et al. (1989) Prevalence of Alzheimer's disease in a community population of older persons. *J Am Med Assoc* 262:2552–2556
- Faden R, Beauchamp T (1986) *A history and theory of informed consent*. Oxford University Press, New York
- Flanery M, Gravdal J, Hendrix P, et al. (1978) Just sign here. *South Dakota J Med* 31(5):33–37
- Fletcher JC (1973) Realities of patient consent to medical research. *Stud Hastings Center* 1(1):39–40
- Flynn LM (1997) Statement. Issues concerning informed consent and protections of human subjects in research: hearings before the Subcommittee on Human Resources of the House Committee on Government Reform and Oversight, 105th Congress
- Folstein MF, Folstein SE, McHugh RR (1975) Mini-mental state. *J Psychiatr Res* 12:189–198
- Garnett RW (1996) Why informed consent? Human experimentation and the ethics of autonomy. *Catholic Lawyer* 36:455–511
- Goodwin JS, Goodwin JM, Garry PJ (1983) Association between nutritional status and cognitive functioning in a healthy elderly population. *J Am Med Assoc* 249(21):2917–2921
- Gray B (1975) *Human subjects in medical experimentation: a sociological study of the conduct and regulation of clinical research*. Wiley, New York
- Grisso T, Appelbaum P (1998) *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. Oxford University Press, New York
- Hansen L, Salmon DP, Galasko D, Masliah E, Katzman R, DeTeresa R et al. (1990) The Lewy body variant of Alzheimer's disease: a clinical and pathological entity. *Neurology* 40:1–8
- Hassar M, Weintraub M (1976) "Uninformed" consent and the wealthy volunteer: an analysis of patient volunteers in a clinical trial of a new anti-inflammatory drug. *Clin Pharmacol Therapeut* 20:379–386
- Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA (2003) Alzheimer disease in the US population: prevalence estimates using the 2000 census. *Arch Neurol* 60:1119–1122
- High DM, Whitehouse PJ, Post SG, Berg L (1994) Guidelines for addressing ethical and legal issues in Alzheimer disease research: a position statement. *Alzheimer's Dis Assoc Disord* 8 (suppl 4):66–74
- Himes CL, Wagner GG, Wolf DA, Aykan H, Dougherty DD (2000) Nursing home entry in Germany and the United States. *J Cross-Cultural Gerontol* 15:99–118
- Howard JM, De Mets D, The BHAT Research Group (1981) How informed is informed consent? *Cont Clin Trials* 2:287–303
- Kahn RL, Goldfarb AI, Pollack M, Peck A (1960) Brief objective measures for the determination of mental status in the aged. *Am J Psychiat* 117:326–329
- Kapp M (1998) Decisional capacity, older human research subjects, and IRBs: beyond forms and guidelines. *Stanford Law Policy Rev* 9:359–365
- Kennedy GJ (2000) *Geriatric mental health care: a treatment guide for health professionals*. Guilford Press, New York
- Keyserlingk EW, Glass K, Kogan S, Gauthier S (1995) Proposed guidelines for the participation of persons with dementia as research subjects. *Perspect Biol Med* 38:319–361
- Klepper H, Roty M (1999) Personal identity, advance directives, and genetic testing for Alzheimer disease. *Genet Test* 3:99–106
- Lakshmanan M, Mion L, Frengley J (1986) Effective low-dose tricyclic and antidepressant treatment for depressed geriatric patients: a double blind study. *J Am Geriatr Soc* 34:421–426
- LeBlang TR, Kirchner JL (1996) Informed consent and Alzheimer disease research: institutional review board policies and practices. In: Becker R, Giacobini E (eds) *Alzheimer's disease from molecular biology to therapy*. Birkhauser, Boston, pp. 529–534
- Levine RJ (1988) *Ethics and regulation of clinical research*. Yale University Press, New Haven, CT
- Loue S (2001) Elder abuse and neglect in medicine and law: the need for reform. *J Legal Med* 22:159–209
- Lubasch AH (1982) Trial ruled in 1953 death case. *NY Times* September 14, pA-14
- Manders M, de Groot CPGM, van Staveren WA, et al. (2004) Effectiveness of nutritional supplements on cognitive functioning in elderly persons: a systematic review. *J Gerontol Ser A: Biol Sci Med Sci* 59:M1041–M1049
- Manning CC (1993) The Medicare Alzheimer's demonstration. *Elder Law J* 1:113–137
- Markesbery WR (1998) *Neuropathology of dementing disorders*. Oxford University Press, New York
- Masliah E, Miller A, Terry RD (1993) The synaptic organization of the neocortex in Alzheimer's disease. *Med Hypotheses* 41:334–340
- McCullum AT, Schwartz AH (1969) Pediatric research hospitalization: its meaning to parents. *Pediatric Res* 3:199–204
- Medical Research Council Working Party on Research on the Mentally Incapacitated (1991) *The ethical conduct of research on the mentally incapacitated: report of the Working Party on Research on the Mentally Incapacitated*. MRC Ethics Series. Medical Research Council, London
- Meisel A, Roth LH, Lidz CW (1977) Toward a model of the legal doctrine of informed consent. *Am J Psychiatry* 134:285–289
- Molloy DW, Alemayehu E, Roberts R (1991) A standardized Mini-Mental State Examination (MMSE). *Am J Psychiatry* 148:102–105
- Morrow G, Gootnick J, Schmale A (1978) A simple technique for increasing cancer patients' knowledge of informed consent to treatment. *Cancer* 42:793–799
- National Bioethics Advisory Commission (2001) *Ethical and policy issues in research involving human participants*, vol. 1. U.S. Government Printing Office, Rockville, MD
- National Institutes of Health (2005) *Certificates of confidentiality Kiosk*. Available at <http://grants1.nih.gov/grants/policy/coc/index.htm> (last accessed February 7, 2005)
- National Institutes of Health Clinical Center (1987) *Policy and communications bulletin: consent process in research involving impaired human subjects*. No. 87-4. Department of Health and Human Services, Rockville, MD
- Oscar-Berman M, Evert DL (1997) Alcoholic Korsakoff's syndrome. In: Nussbaum PD (ed) *Handbook of neuropsychology and aging*. Plenum Press, New York, pp. 201–215

- Park LC, Slaughter RS, Covi L, Kniffin HG Jr (1966) The subjective experience of the research patient: an investigation of psychiatric outpatients' reactions to the research treatment situation. *J Nervous Mental Dis* 143:199–206
- Park LC, Covi L, Uhlenhuth EH (1967) Effects of informed consent on research patients and study results. *J Nervous Mental Dis* 145 (5):349–357
- Petersen RC, Stevens JC, Ganguli M, Tangalos EG, Cummings JL, De Kosky ST (2001) Practice parameter: early detection of dementia: mild cognitive impairment (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 56: 1133–1142
- Post SG (1995) Alzheimer disease and the "then" self. *Kennedy Inst Ethics J* 4:307–321
- Riecken HW, Ravich R (1982) Informed consent to biomedical research in Veterans Administration hospitals. *J Am Med Assoc* 248(3):344–348
- Roman GC (1991) The epidemiology of vascular dementia. In: Hartmann A, Kuschinsky W, Hoyer S (eds) *Cerebral ischemia and dementia*. Springer, Berlin, pp. 9–15
- Rothman DJ (1991) *Strangers at the bedside: a history of how law and bioethics transformed medical decision making*. Basic Books, New York
- Sachs GA (1994) Advance Consent for dementia research. *Alzheimer Dis Associated Disord* 8:19–27
- Sachs G, Cassel C (1989) Ethical aspects of dementia. *Neurol Clin* 7:845–858
- Sachs GA, Stocking CB, Stern R, Cox DM, Hougham G, Sachs RS (1994) Ethical aspects of dementia research: informed consent and proxy consent. *Clin Res* 42:403–412
- Salmon DP, Bondi MW (1997) The neuropsychology of Alzheimer's disease. In: Nussbaum PD (ed) *Handbook of neuropsychology and aging*. Plenum Press, New York, pp. 141–158
- Scott v. Casey (1983) 562 F. Supp. 475 (N.D. Ga.)
- Solomon PR, Hirschhoff A, Kelly B, et al. (1998) A 7-minute neurocognitive screening battery highly sensitive to Alzheimer's disease. *Arch Neurol* 55:349–355
- Stahelin HB, Monsch AU, Spiegel R (1997) Early diagnosis of dementia via a two-step screening and diagnostic procedure. *Int Psychogeriatr* 9:123–130
- Tatara T (1995) *An Analysis of State Laws Addressing Elder Abuse, Neglect, and Exploitation*. National Center on Elder Abuse, Washington, DC
- Uhlenhuth EH, Park LC (1964) The influence of medication (imipramine) and doctor in relieving depressed psychoneurotic outpatients. *J Psychiatric Res* 2:101–122
- United States Census Bureau (2001a) *The 65 years and over population: 2000*. Census 2000 Brief. United States Census Bureau, Washington, DC
- United States Census Bureau (2001b) *Statistical brief: sixty-five plus in the United States*. United States Census Bureau, Washington, DC. Available at <http://www.census.gov/population/socdemo/statbriefs/agebrief.html> (last accessed November 9, 2004)
- Unverzagt FW, Gao S, Baiyewu O, et al. (2001) Prevalence of cognitive impairment: data from the Indianapolis Study of Health and Aging. *Neurology* 57(9):1655–1662
- Usman MA (1997) Frontotemporal dementia. In: Nussbaum PD (ed) *Handbook of neuropsychology and aging*. Plenum Press, New York, pp. 159–175
- Valenti v. Prudden (1977) 58 A.D.2d 956, 397 N.Y.S.2d 181
- Williams RL, Rieckmann KH, Trenholme GM, Frischer H, Carson PE (1977) The use of a test to determine that consent is informed. *Military Med* 142:542–545

