



End-of-Life Care: Services, Costs, Ethics, and Quality of Care

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Summary

End-of-life care can be broadly defined as health care provided to persons who are very ill, have a prognosis that is likely to worsen, and most likely will die in the near term from their illness. End-of-life care may be in the form of acute care provided in the days or months prior to death or palliative care, which focuses on relieving the patient's suffering and reducing the severity of disease symptoms as well as improving quality of life. Hospice care is a form of palliative care that delivers comfort care to those who forgo curative treatment and have a life expectancy that can be measured in months. Achieving a health care system where the provision of end-of-life care services are sensitive to and accommodate the needs of all those involved requires attention to a range of ethical and policy issues, including personal choice, cost, and quality of care.

Over the past century, several demographic and historical changes have affected the experience of death and dying in the United States. The development of new technologies, and the associated prospect of longer, more protracted deaths, has focused some policy discussions on the topic of patients' preferences. Federal law generally defers to state law concerning health-care decision making. Given the complexities in decision making surrounding medical interventions that have life-extending potential, states have passed laws to address end-of-life care issues, such as advance directives. However, there is considerable variation among state laws.

Costs of care at the end of life may be paid by Medicare or Medicaid, private insurance, or out-of-pocket. According to CMS, about one-fourth of total Medicare spending is for the last year of life. This share has remained generally constant for the past 20 years. The majority of Medicare end-of-life costs are from inpatient hospital expenditures. Researchers have also found that there is wide geographic variation in end-of-life Medicare costs. This geographic variation may reflect differences in practice patterns of physicians and is not necessarily due to differences in prevalence of disease among chronically ill patients.

End-of-life care presents numerous challenges and opportunities for quality measurement, assessment, and improvement. Assessments of quality end-of-life care are often based on family and patient satisfaction. Factors associated with perceptions of higher quality care include expressions of patients' wishes, discussions of families' spiritual needs, documentation of a living will, and family presence at the time of death. A number of initiatives are currently underway to improve the quality of care individuals receive at the end of life, and specifically the quality of palliative and hospice care.

As the nation prepares for an aging population and likely increase in the need for high quality end-of-life care services among the elderly, Congress may face a decision whether to expand the role of the federal government in providing support to individuals and families to assist with end-of-life care. This report provides information on various aspects of end-of-life care. The report is divided into six sections that address (1) demographic and historical changes affecting death and dying in the United States; (2) the definitions of end-of-life, palliative, and hospice care; (3) costs associated with end-of-life care; (4) end-of-life care laws and ethics; (5) quality of care at the end of life; and (6) policy issues that would modify or expand the federal government's role in addressing end-of-life care. This report will be updated as warranted.

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Death and Dying: Demographic and Historical Changes

“Death, a necessary end, will come when it come,”¹ is a portion of a Shakespeare quotation that speaks to the inevitability of death. Death is common to all who are living. It is the eventual consequence of life. And despite its commonality and pervasiveness, death has a profound and distinct effect on each person that it touches—each dying person, each loved one, each friend and colleague, and each health care provider. “Dying is at once a fact of life and a profound mystery.”² Achieving a system of end-of-life care that is sensitive to and accommodates the needs of all those involved, requires attention to a range of ethical and policy issues, including personal choice, cost, and quality of care.

Over the past century, several demographic and historical changes have affected the experience of death and dying in the United States. These changes include increases in the average lifespan; growth in the size and proportion of the older U.S. population; changes in the leading causes of death; and advances in medicine and medical interventions that have altered the setting and timing of death. The following briefly describes these demographic and historical changes as they relate to the experience of death and end-of-life care in the United States. Lastly, an understanding of culture notions of death in the U.S. and how the current health care system may work against the concept of a “good” death are described in this section.

Life Expectancy

In the early 20th century most Americans died young. In 1900, the average life expectancy at birth for men and women combined was 49.2 years of age. Few Americans lived past the age of 65 or into “old-age.”³ Since then, average life expectancy has risen dramatically in the United States. More than a century later, in 2004, average life expectancy for both sexes had increased by 28.6 years to 77.8 years of age.⁴ Increases in average life expectancy since the early 1900’s have been largely attributable to reductions in child mortality. Since the 1950s, increases in average life expectancy have been both a result of improvements in the prevention and control of chronic diseases as well as advances in medical interventions and pharmaceuticals.⁵ While important differences in longevity still remain across certain demographic groups (e.g., gender, race, socioeconomic status), increases in average life expectancy mean that more Americans are experiencing living and dying in “old-age.” As a result, many older Americans may need long-term care services and supports to address increasing frailty and loss of physical or cognitive

¹ William Shakespeare, *Julius Caesar*, Act II, Scene 2, line 32.

² Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, National Academy Press: Washington, DC, 1997, p. 1.

³ Yelena Gorina, Donna Hoyert, Harold Lentzner, et al., *Trends in Health and Aging: Trends in Causes of Death among Older Persons in the United States*, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Aging Trends No. 6, Hyattsville, MD, October 9, 2005.

⁴ Federal Interagency Forum on Aging-Related Statistics, *Older Americans: Key Indicators of Well-Being, Federal Interagency Forum on Aging-Related Statistics*, Washington, DC: U.S. Government Printing Office, March 2008.

⁵ For further information see, CRS Report RL34125, *Mortality of Americans Age 65 and Older: 1980 to 2004*, by (name redacted).

functioning, chronic degenerative diseases, or terminal illnesses that may also lead to the need for end-of-life care in advanced age.

Age Distribution

The past century has also seen a dramatic growth in both the size and proportion of the population age 65 and older. This growth has recently been accelerated by the aging of the baby boom generation. Population aging affects end-of-life care in that most deaths in the United States now occur among the aged. Preliminary data from the Centers for Disease Control and Prevention (CDC) indicate that more than 2.4 million Americans died in 2006 (see **Table 1**), with 7 in 10 deaths occurring among those age 65 and older. Thus, as the U.S. population ages, the number of patients age 65 and older receiving end-of-life care is also expected to grow.

Table 1. Deaths in the United States by Age Group, Preliminary 2006

Age Group	Number	Percent (%)
Under 35 years	117,082	4.8
35 to 64 years	548,912	22.6
65 to 84 years	1,057,715	43.6
85 years and over	701,923	28.9
Total	2,425,900	100.0

Source: CRS compilation based on data from the Centers for Disease Control and Prevention, *National Vital Statistics Reports*, Table 1, vol. 56, no. 16, June 11, 2008.

Notes: Figures are based on weighted data rounded to the nearest individual, so categories may not add to total number or percent. Total category includes 266 individuals where age was not specified.

Leading Causes of Death

Changes in the leading causes of death among Americans have affected how people experience death. In the early half of the 20th century, most Americans died from infectious diseases. For example, in 1900 the leading causes of death were pneumonia, tuberculosis, and diarrhea and enteritis.⁶ Thus, for the majority of the U.S. population, death was experienced rapidly and with a great deal of certainty.⁷ Due to achievements in modern medicine in the first half of the 20th century (e.g., vaccination, antibiotics) and changes in personal behavior, diseases that may have been fatal in the past now are effectively managed for years. As a result, many Americans are living longer with chronic conditions or degenerative diseases, but also dying from them. In 2006, heart disease was the leading cause of death among Americans, followed by cancer, and stroke. Many of these chronic conditions give rise to the need for continuing health care and can be resource intensive, generating significant costs for treatments and/or the need for long-term care (e.g., dialysis, transplant surgery, respiratory therapy, and personal care) and end-of-life care. Death in the early 21st century for most Americans can be characterized by a gradual onset of

⁶ Centers for Disease Control and Prevention, "Achievements in Public Health, 1990-1999: Control of Infectious Diseases," *Morbidity and Mortality Weekly Report*, vol. 48, iss. 29 (July 30, 1999), pp. 621-629.

⁷ American Psychological Association, "End-of-Life Issues and Care: Historical Changes Affecting End-of-Life Care," at <http://www.apa.org/pi/eol/historical.htm>.

disease that leads to a slow decline in an individual's health and ability to maintain their functional independence, ultimately resulting in a dying process that can be longer in duration and much less predictable.

Location and Timing of Death

Other changes that affect end-of-life care in the United States include the location and timing of death. In the early 20th century most deaths occurred in the home. Over the century that trend reversed to one where death largely occurs in an acute care setting. Estimates using data from the most recent national survey that looks at demographic trends in mortality found that in 1993 the majority of deaths among all age groups in the United States occurred in hospitals (58%), while 22% occurred in the home, and 20% occurred in a nursing home.⁸ Further evidence suggests that the location of death can vary substantially by underlying cause of death. In a 2001 study of over 1.74 million nontraumatic deaths of persons age 65 and older, two-thirds of individuals whose underlying cause of death was dementia died in a nursing home (67%), compared to 21% whose underlying cause of death was cancer and 28% who had some other condition that resulted in death.⁹ However, some experts believe that with the greater availability of home and community-based services and home hospice services the trend may be reversing among those who know they are dying, increasing the proportion of those who die at home.¹⁰ Moreover, evidence suggests that family members of loved ones who died in a private home with hospice services were more likely to report a favorably dying experience compared to those whose loved one died in an institutional setting such as a hospital or nursing home.¹¹

The increase in deaths occurring in institutional settings is also a reflection of medical and technological advances that can permit life to be extended. These advancements, particularly related to life-prolonging treatments, have created a range of outcomes for individuals and for society. Yet, "many people have become fearful that the combination of old age and modern medicine will inflict on them a dying that is more protracted and, in some ways, more difficult than it would have been a few decades ago."¹² On the other hand, "while an overtreated dying is feared, the opposite medical response—abandonment—is likewise frightening."¹³ The ability to strike the appropriate balance between treatment and non-treatment can prove difficult for health providers and policymakers alike.

Technological advances in health care present individuals, families, and medical professionals with difficult decisions about the timing of the dying process. As a result of the complexities surrounding decisions regarding medical treatment to extend life, medical professionals have exerted more influence over the decision making process. For example, 95% of general hospitals

⁸ Sherry Weitzen, Joan Teno, Mary Fennell, et al., "Factors Associated with Site of Death: A National Study of Where People Die," *Medical Care*, vol. 41, no. 2 (February 2003), pp. 323-335.

⁹ Susan L. Mitchell, Joan M. Teno, Susan C. Miller, et al., "A National Study of the Location of Death for Older Persons with Dementia," *Journal of the American Geriatrics Society*, vol. 53, no. 2 (February 2005), pp. 299-305.

¹⁰ American Psychological Association, "End-of-Life Issues and Care: Historical Changes Affecting End-of-Life Care," at <http://www.apa.org/pi/eol/historical.htm>.

¹¹ Joan Teno, Brian Clarridge, Virginia Casey, et al., "Family Perspectives on End-of-Life Care at the Last Place of Care," *Journal of the American Medical Association*, vol. 291, no. 1 (January 7, 2004), pp. 88-92.

¹² Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, National Academy Press: Washington, DC, 1997, p. 14.

¹³ *Ibid.*, at p.15.

surveyed in 1999 and 2000 offered ethics consultation or were starting up a consult service.¹⁴ More recently, public attitudes have shifted toward encouraging active participation of individuals and families in medical decision making regarding end-of-life care. This trend is likely to continue with the aging of the baby-boom generation.

Another technology-associated factor that emerges in public policy discussions is that the cost of health care at the end of life—and throughout life—has increased. In turn, this increase has raised questions about the appropriate distribution of expensive health care resources across the lifespan. Further complicating this policy discussion is data indicating regional variation in spending intensity at the end of life.¹⁵ Some have suggested that provider reimbursement, rather than patient care, may drive this spending.¹⁶ Each of these factors are issues for end-of-life care policymakers and are discussed in further detail in the report section on “Cost of Care at End-of-Life.”

Cultural Notions of Death in the U.S.

It has been said that Americans are the only individuals on earth who believe that death is negotiable. For many, conversations about death may be uncomfortable or even feared and thus avoided or deemed taboo. Still, only through the contemplation of one’s own mortality can a person formulate and articulate his or her wishes. One concept that is working toward changing individuals’ attitudes about death is the idea that one can achieve a “good” death. The notion of a good death has been described in a number of ways, including one that is: free from pain and suffering; reasonably consistent with clinical, cultural and ethical standards; in the company of loved ones; following the opportunity for reconciliation; arriving with reasonable warning; and reflective of peace, meaning, or transcendence significant to the individual.

However, observers have noted that the U.S. health care system may work against the good death concept through health care provider’s use of combative language when referring to death and disease. For example, death is often described as an enemy with the fight against disease characterized as a battle. Health care providers’ desire to forestall death may be a positive attribute, or at least understandable. However, one consequence of the use of this type of language is that allowing death is perceived as akin to loss or failure:

Physicians realize, of course, that the mission of vanquishing death is finally futile, but often they ... are quite determined to do all that is possible to postpone the event. Sometimes this objective so dominates care that patients undergo therapies whose effects do not actually advance their own goals and values.¹⁷

In some cases, individuals might want health providers to assist in the fight against disease and ultimately death. However, in other cases, they might be better served by health providers’ efforts

¹⁴ The role of these committees was cemented in 1992 when the Joint Commission on Accreditation of Healthcare Organizations mandated that health care organizations come up with some way of addressing ethical concerns. Kevin B. O’Reilly, “Willing, but waiting: Hospital ethics committees,” *Amdnews.com*, January 28, 2008, at <http://www.ama-assn.org/amednews/2008/01/28/prsa0128.htm>.

¹⁵ A.E. Barnato, M.B. Herndon, D.L. Anthony, et al., “Are Regional Variations in End-of-Life Care Intensity Explained by Patient Preferences?” *Medical Care*, vol. 45, no. 5 (May 2007), p. 386.

¹⁶ *Ibid.*, at p. 387.

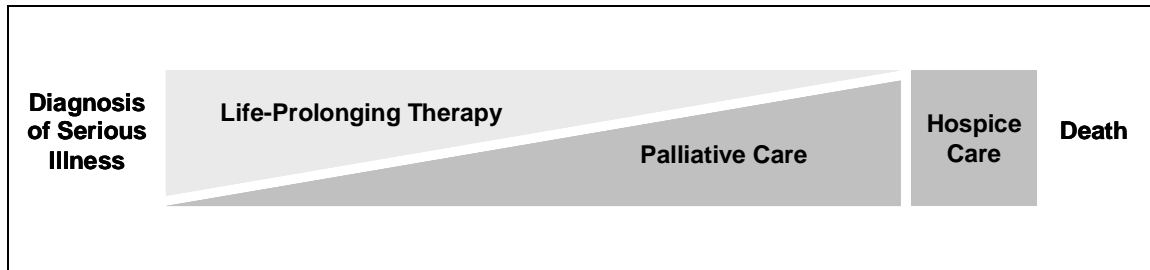
¹⁷ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Decisions to Forego Life-Sustaining Treatment* (Washington, DC: GPO, March 1983), p. 15.

to enhance their quality of life, and then acting as guides during transition into death. A 1997 IOM committee tasked with studying end-of-life care in the U.S. concluded that serious problems in providing quality end-of-life care remain.¹⁸ Specifically, the committee identified errors of omission, where health providers fail to provide care that is known to be effective in alleviating pain and providing comfort at the end of life, as well as errors of commission, or care that is known to be ineffective and may be harmful.¹⁹

What Is End-of-Life Care?

End-of-life care can be broadly defined as health care, including acute care and long-term care, provided to persons who: are very ill, have a prognosis that is likely to worsen, and most likely will die from their illness.²⁰ Those diagnosed with a serious or terminal illness experience health declines associated with the disease and the dying process differently. As a result, there is not necessarily a boundary between when life-prolonging therapy ends and end-of-life care begins. Palliative care is one form of health care that can assist those diagnosed with a terminal illness as well as others who have a chronic disease or serious illness. Hospice care is a form of palliative care specifically for those at the end of life. (See **Figure 1**). The following briefly describes the concepts of palliative care and hospice care. Additional information is also provided on hospice providers and patients.

Figure 1. Palliative and Hospice Care's Place in the Course of Illness



Source: CRS adaptation from the Center to Advance Palliative Care, "Definition of Palliative Care," at <http://www.allhealth.org/BriefingMaterials/DianeMeier-PalliativeCare-762.pdf>.

Palliative Care

Palliative care is a medical specialty that is both a philosophy of care and a process for delivering care. The term "palliate" means to "relieve or lessen without curing; mitigate; alleviate."²¹ Palliative care focuses on relieving suffering and reducing the severity of disease symptoms for persons with serious illness as well as improving the quality of life for patients and their families.

¹⁸ Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, National Academy Press: Washington, DC, 1997.

¹⁹ Ibid.

²⁰ Anne Wilkinson, "Factors Associated with Family Caregivers' Experience of End-of-Life Care," paper presented at the Academy Health Annual Research Meeting, Boston, Massachusetts, June 28, 2005, at <http://www.academyhealth.org/2005/>.

²¹ Dictionary.com Unabridged, "palliative," based on the Random House Dictionary, Random House, Inc., 2009, at <http://dictionary.reference.com>.

While the purpose of palliative care is not to halt or delay disease progression or cure illness, it can be delivered along with curative treatment at anytime during the course of a person's illness. The World Health Organization (WHO) defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.²²

In order to address the complex needs of seriously ill patients and their families, palliative care is generally delivered through an interdisciplinary team of health care professionals in both acute care settings, such as hospitals, and long-term care settings, such as nursing homes. Members of a palliative care team typically include physicians, nurses, social workers, and psychologists, with additional assistance from chaplains, nutritionists, rehabilitation therapists, pharmacists, and other professional disciplines. According to one study, the prevalence of hospital palliative care programs in the United States has steadily increased since 2000, with 53% of hospitals reporting a palliative care program in 2006 compared to 25% in 2000.²³ However, the authors also found wide variation in access to palliative care services based on several factors including hospital size, public versus for profit hospital status, and medical-school affiliation.

Professional interest in advancing training and education in palliative care among the medical community has also taken shape. The 1997 IOM study recommended changes in undergraduate, graduate, and continuing education for health professionals to ensure practitioners have the "relevant attitudes, knowledge, and skills to care well for dying patients."²⁴ The IOM study also recommended that palliative care should become a defined area of expertise, education, and research, if not a medical specialty. Nearly a decade later, the American Board of Medical Specialties (ARMS) voted to establish Hospice and Palliative Medicine as a new medical subspecialty in 2006. Earlier that same year, the Accreditation Council for Graduate Medical Education (ACGME) approved an accreditation process for hospice and palliative care fellowship programs.

Hospice Care

The term "palliative care" should not be confused with "hospice care." Hospice care is a form of palliative care that delivers comfort care to those at the end of life. Both hospice care and palliative care share the same goals of alleviating pain and suffering and improving quality of life for patients. However, hospice care is focused on terminally ill patients, who no longer seek curative medical treatment, and who, generally, are expected to live for about six months or less. Hospice provides a patient-centered approach to care that involves both the patient and family in decision making about care at the end of life.

²² World Health Organization, "WHO: Definition of Palliative Care," at <http://www.who.int/cancer/palliative/definition/en/>.

²³ B. Goldsmith, J. Deitrich, Q. Du, et al., "Variability in Access to Hospital Palliative Care in the United States," *Journal of Palliative Medicine*, vol. 11, no. 8 (2008), pp. 1094-1103.

²⁴ Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, National Academy Press: Washington, DC, 1997.

The first hospice program in the United States opened in 1974 in New Haven, Connecticut.²⁵ In the late 1970s, the U.S. Department of Health, Education and Welfare (now the U.S. Department of Health and Human Services) published a report citing hospice as a viable concept of care for terminally ill people and their families that provides humane care at a reduced cost.²⁶ A year later, the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) started hospice demonstration projects across the nation. The purpose of these projects was “to assess the cost effectiveness of hospice care and help determine what a hospice program was and what services could be provided.”²⁷ In the early 1980s, the Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248) established Medicare coverage for hospice care. To be eligible for the Medicare hospice benefit beneficiaries must be certified by their attending physician, and the hospice physician, as being terminally ill with a life expectancy of six months or less if the disease follows its “normal course.”²⁸ Today, most states also provide hospice Medicaid coverage. Hospice care can also be a covered service under private health insurance plans or paid for out-of-pocket by individuals.

The National Hospice and Palliative Care Organization (NHPCO) estimated that 1.4 million patients received services from hospice care providers in 2007. This estimate includes 930,000 patients who died under hospice care, another 258,000 who were admitted to hospice in 2007 but continued to receive care into 2008, and approximately 222,000 patients who were discharged alive. These discharges may be due to an extended prognosis or desire to seek curative treatment. Among all deaths in the United States in 2007, NHPCO estimated that 39% were patients under the care of a hospice program.²⁹ This estimate is similar to earlier estimates of Medicare decedents use of the hospice benefit. According to the Medicare Payment Advisory Commission (MedPAC), in 2005, roughly 40% of Medicare decedents used the hospice benefit under the Medicare program, up from 27% in 2000.³⁰ This increase may be due in part to physician familiarity and acceptance of palliative medicine, changes in the Medicare payment system for hospice care, as well as changes in cultural attitudes surrounding end-of-life care. Medicare hospice covers the largest percentage of hospice patients (84% in 2007), compared to other payment sources such as Medicaid (5%), private insurance and managed care (8%), and other (3%).³¹

Settings

Hospice care can be provided in a variety of settings such as a private residence, a long-term care facility such as a nursing home, or a residential care facility such as an assisted living facility. Some hospice providers also operate a dedicated inpatient unit or freestanding hospice facility. According to NHPCO, most hospice patients die in their own residence or the “place they call

²⁵ Hospice Foundation of America, at <http://www.hospicefoundation.org/>.

²⁶ National Hospice and Palliative Care Organization, “Hospice: A Historical Perspective,” at <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3285>.

²⁷ *Ibid.*

²⁸ MedPAC, “Report to Congress: Reforming the Delivery System, Chapter 8: Evaluating Medicare’s hospice benefit,” MedPAC, Washington, DC, June 2008 (hereinafter referred to as MedPAC, Report to Congress, 2008).

²⁹ National Hospice and Palliative Care Organization, “NHPCO Facts and Figures: Hospice Care in America,” October 2008 (hereinafter referred to as NHPCO Facts and Figures, 2008).

³⁰ MedPAC, Report to Congress, 2008.

³¹ NHPCO Facts and Figures, 2008.

home.”³² That is, an estimated three out of every four hospice patients (70.3%) died in a private residence, nursing home, or other residential care facility compared to an acute hospital setting not managed by a hospice organization (10.5%). Another 19.2% died in a hospice facility.

Table 2. Hospice Patient’s Location of Death, 2007

Location of Death	2007
Patient’s place of residence	70.3%
Private residence	42.0%
Nursing facility	22.8%
Residential facility	5.5%
Hospice inpatient facility	19.2%
Acute care hospital	10.5%

Source: National Hospice and Palliative Care Organization, “NHPCO Facts and Figures: Hospice Care in America,” October 2008.

Length of Stay

The NHPCO reports that the average length of stay for a patient receiving hospice care was 67.4 days in 2007, an increase from 59.8 days in 2006. The median length of stay, which may be a better measure for understanding the experience of the typical hospice patient, was 20.0 days in 2007, a slight decline from 20.6 days in 2006.³³ According to MedPAC, most hospice patients have episodes that are less than six months; however, the number of long episodes has been increasing. For example, Medicare hospice beneficiaries at the 90th percentile for length of stay had stays of 212 days, a nearly 50% increase from 2000.³⁴ According to NHPCO, there are several factors that can influence a hospice patient’s length of stay including the course of the disease, the timing for referral to hospice, and patient’s access to care.³⁵

Services

Hospice care provides a variety of services to assist patients in maintaining a high-quality and pain-free life, at the last stage of life. Care is provided by an interdisciplinary team of health care professionals as well as family caregivers and volunteers with the goal of providing services according to the patient’s individual needs and preferences. Hospice services can include nursing care; social services; physicians’ services; counseling; medical equipment and supplies; prescription drugs; and physical, occupational, and speech therapy. Other hospice services, such as personal care, provided by a family member or paid caregiver such as a home health aide, can assist patients with their basic activities of daily living (e.g., eating, bathing, dressing, toileting). Hospice care also provides respite care, which provides family caregivers with temporary relief from their caregiving responsibilities. In addition, hospice care can provide bereavement support for both family members and hospice patients.

³² Ibid.

³³ Ibid.

³⁴ MedPAC, Report to Congress, 2008.

³⁵ NHPCO Facts and Figures, 2008.

Patient Characteristics

In the 1970's, terminal cancer patients were the largest percentage of hospice admissions. However, over the past three decades the proportion of non-cancer admissions has increased.³⁶ In 2007, almost six in ten (59%) hospice patients were admitted with a non-cancer related primary diagnosis such as heart disease, dementia (including Alzheimer's disease), or lung disease.³⁷ Earlier data from CMS indicate that from 1999 to 2005 the fastest growing non-cancer diagnoses are Alzheimer's disease, debility not otherwise specified, adult failure to thrive, and senile dementia. According to CMS, these diagnoses are also associated with "very long lengths of stay."³⁸

In terms of the demographic characteristics of the hospice population, in 2007 over half of hospice patients were female (53.9%) versus 46.1% male. The vast majority were 65 years of age and older (82.8%), with over one-third (36.6%) of all hospice patients 85 years of age and older. Data for race and ethnicity follow the Census guidelines in reporting race as a separate concept from ethnicity. In 2007, 5% of patients reported being of Hispanic or Latino origin, while almost 20% of hospice patients were minorities (black/African American; Asian, Hawaiian, or other Pacific Islander; American Indian or Alaskan Native; and Multiracial or other race).³⁹

Providers

Hospices organizations may be independent or freestanding agencies or organizations based within a hospital, home health agency, or nursing home. In 2007, more than half of hospices were free standing or independent agencies (58.3%), another 20.8% were hospital based, 19.7% were home health based, and a small percentage were nursing home based (1.3%). Data from the NHPCO indicate that the number of hospice providers continues to increase. In 1997, there were an estimated 3,000 hospice providers, by 2007 that number had increased over 50% to 4,700.⁴⁰ Slightly less than half (48.6%) of hospice providers in 2007 had a not-for-profit tax status, 47.1% had a for-profit status, and the remaining 4.3% were government-run programs through the Department of Veterans Affairs medical centers and county-run hospices. NHPCO states that most of the recent growth is in small free-standing and for-profit providers. Not all hospices are certified to participate in Medicare. According to 2006 data from MedPAC, 3,069 hospices (68% of all hospice providers) were certified to participate in the Medicare program.⁴¹

Role of Family Caregivers

Family caregivers engage in a variety of activities for their loved ones receiving end-of-life care including providing emotional support, assistance with personal care and medications, and

³⁶ Centers for Medicare and Medicaid, "Medicare Hospice Data: 1998-2005," December 27, 2007 at <http://www.cms.hhs.gov/center/hospice.asp> (hereinafter referred to as CMS, Medicare Hospice Data: 1998-2005).

³⁷ NHPCO Facts and Figures, 2008.

³⁸ CMS, Medicare Hospice Data: 1998-2005.

³⁹ NHPCO Facts and Figures, 2008.

⁴⁰ Data for 2008 are from National Hospice and Palliative Care Organization, "NHPCO Facts and Figures: Hospice Care in America," October 2008; Data for 1997 are from National Hospice and Palliative Care Organization, "NHPCO Facts and Figures: Hospice Care in America," November 2007.

⁴¹ MedPAC, Report to Congress, 2008.

communication with health professionals. Research suggests that care provided by family caregivers can be extremely demanding on the caregiver.⁴² However, there is little data or information on supportive interventions that are effective in assisting caregivers.⁴³ Some family caregivers facing intense caregiving burden up to the point of the family member's death may even report "relief" from the death. Respite care, counseling, and bereavement services offered under the range of services provided by hospice may assist family caregivers both prior to the family member's death and with the process of grieving after their death.

Cost of Care at the End of Life

Costs of care at the end of life may be paid by public payers such as Medicare or Medicaid, private insurance, out-of-pocket, or by some other source such as the Department of Veterans Affairs or charity organizations. Much of the data available on end-of-life care costs are for Medicare beneficiaries, thus this section focuses on analyses conducted on costs to the Medicare program for care at the end of life.

About one-fourth of total Medicare spending is for the last year of life. This share has remained generally constant for the past 20 years.⁴⁴ As previously mentioned, end-of-life care includes acute care often provided in a hospital setting or palliative care within a hospice setting. In addition, the predictability and timing of an individual's death may determine the setting for end-of-life care. For example, beneficiaries who are terminally ill may become more involved in decisions about their end-of-life care. Those terminally ill individuals—with a life expectancy of six months or less—may reject curative treatment and instead elect to receive hospice care under Medicare. Conversely, individuals with acute medical conditions may die unexpectedly. These individuals may receive aggressive and expensive procedures in a hospital setting prior to their death.⁴⁵ As a result, end-of-life care costs under Medicare generally vary by setting. Further research suggests there is variation in end-of-life care costs by geographic region. The following describes these variations in Medicare costs for end-of-life care in further detail.

Setting of Care

The majority of Medicare end-of-life costs, defined as Medicare spending in the last two years of life, are from inpatient hospital expenditures. **Figure 2** shows that 56% of end-of-life costs under Medicare—during the period of 2001 to 2005—were in an acute care hospital setting. These hospital costs include not only hospital inpatient facility charges, but also payments for inpatient physician visits, procedures, and diagnostic tests. Other sites of care comprised a much smaller share of end-of-life costs. Spending for outpatient and skilled nursing facility services each

⁴² Richard Schulz, Aaron B. Mendelsohn, William E. Haley, et al., "End-of-Life Care and the Effects of Bereavement on Family Caregivers of Persons with Dementia," *The New England Journal of Medicine*, vol. 349, no. 20 (November 13, 2003), pp. 1936-1942.

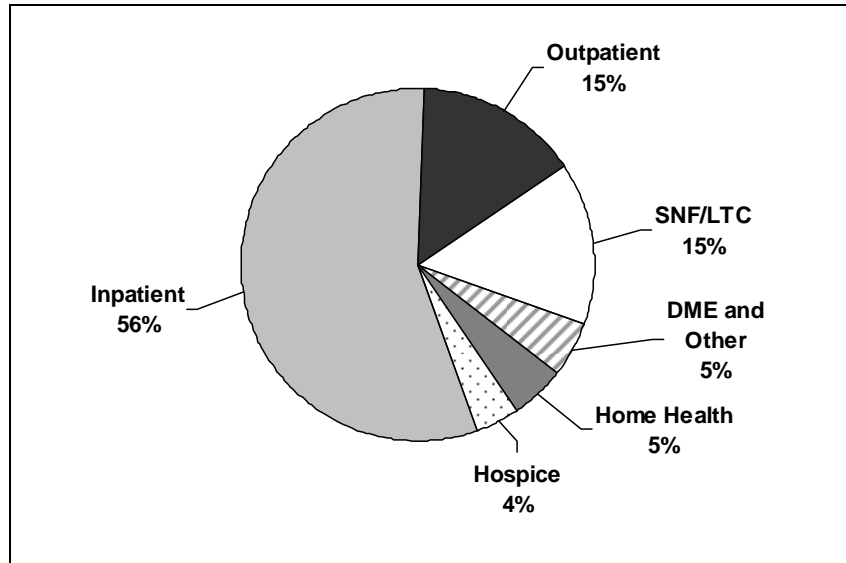
⁴³ National Institutes of Health, "NIH State-of-the-Science Conference Statement on Improving End-of-Life Care," U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health, Office of Medical Applications Research, vol. 21, no. 3, December 6-8, 2004, p. 13.

⁴⁴ C. Hogan, June Lunney, Jon Gabel, et al., "Medicare Beneficiaries' Costs of Care in the Last Year of Life," *Health Affairs*, vol. 20, no.4 (July/August 2007), pp. 188-1.

⁴⁵ Brenda E. Sirovich, Daniel J. Gottlieb, H. Gilbert Welch, et al., "Variation in the Tendency of Primary Care Physicians to Intervene," *Archives of Internal Medicine*, vol. 165, no. 19 (October 24, 2005), pp. 2252-2256.

comprised about 15% of end-of-life costs. Home health spending was 5% and hospice spending accounted for 4% of end-of-life costs.⁴⁶ Note that this data measures end-of-life care over the last two years of a Medicare decedent's life. While inpatient hospital services accounted for the majority of Medicare spending at the end of life, costs for inpatient hospital care are also the largest spending category for Medicare in general, comprising 30% of total Medicare spending in 2007.⁴⁷ Thus, this data may not measure greater usage of inpatient hospital expenses at the end of life, but rather more expensive care that is generally provided in a hospital setting.

Figure 2. Sources of Medicare Spending During Last Two Years of Life, 2001 to 2005



Source: Prepared by CRS using data from Wennberg et al., "Tracking the Care of Patients with Severe Chronic Illness: The Dartmouth Atlas of Health Care," The Dartmouth Institute, April 2008.

Notes: SNF/LTC refers to skilled nursing facility/long-term care facility; DME refers to durable medical equipment.

Some have argued that health care costs are lower when hospice care is substituted for intensive care in a hospital. At the individual level, spending can depend on the circumstances of each patient, including the nature and course of the disease, access to curative and palliative care, the presence of family or other social support system, and the patient's own religious or personal views of death. At the aggregate level, the differences may depend on the time period over which costs are measured. When measured over the last six months of life, the cost of hospice care has been shown to be between 10% to 17% less expensive than the cost of intensive care in a hospital setting.⁴⁸ The same study, however, found that savings from hospice use was not as great when health care spending is viewed over an individual's last full year of life (rather than just the last six months). When measured over this longer time period, the savings from using hospice care

⁴⁶ J. Wennberg, E. Fisher, D. Goodman, et al., "Tracking the Care of Patients with Severe Chronic Illness: The Dartmouth Atlas of Health Care," The Dartmouth Institute, April 2008 (hereinafter referred to as Wennberg Study).

⁴⁷ Medicare Payment Advisory Commission, *A Data Book: Healthcare Spending and the Medicare Program*, June 2008. Note that in addition to the 30%, some share of physician services (which currently comprise 14% of Medicare spending) are related to inpatient hospital care.

⁴⁸ E.J. Emanuel, "Cost Savings at the End-of-Life. What Do the Data Show?" *Journal of the American Medical Association*, vol. 275, iss. 24 (June 26, 1996).

declines to between 0% to 10%.⁴⁹ This is because patients with terminal illnesses may have expensive cancer treatments or experience high medical costs from the treatment of chronic degenerative diseases which could lead to higher health care costs prior to receiving hospice care.

Yet, even within a hospice setting, spending per user has increased. Between 2004 and 2005, hospice spending per user increased by nearly 8%, as overall spending on hospice care grew more than double that rate by 18%.⁵⁰ As shown in **Table 3**, this increase cannot be fully explained by increases in Medicare enrollment or increases in Medicare costs in general. During the same time period, Medicare enrollment increased 1.7% and per capita spending increased 6.9%.⁵¹ As previously mentioned, one reason for the increase in hospice expenditures is that length of hospice stays have increased. Increased lengths of stays may be attributed, in part, to changes in patient mix which has resulted in a higher share of patients having conditions such as Alzheimer’s disease, nonspecific debility, and congestive heart failure. As a result, their timing of death is not as predictable.⁵²

Table 3. Growth Rates in Medicare Hospice Expenditures Relative to Medicare Enrollment and Per Capita Spending, 2004 to 2005

	Year		Percent Change
	2004	2005	
Medicare Hospice Expenditures (\$ in billions)	\$6.89	\$8.15	18.2%
Average Amount Per Hospice User	\$8,713	\$9,382	7.7%
Number of Medicare Beneficiaries (in millions)	41.7	42.4	1.7%
Medicare Spending Per Beneficiary	\$7,266	\$7,765	6.9%

Source: CRS calculation based on data from MedPAC, Centers for Medicare and Medicaid Services, Medicare Hospice Data 1998- 2005, http://www.cms.hhs.gov/ProspMedicareFeeSvcPmtGen/downloads/FY05update_hospice_expenditures_and_units_of_care.pdf; and Medicare Trustees Report, 2005 and 2006.

Geographic Variation

Findings from the same study that addressed sources for end-of-life care spending under Medicare found that there is also wide geographic variation in end-of-life care costs. According to the Wennberg Study, this geographic variation may reflect differences in practice patterns of physicians and are not necessarily due to differences in prevalence of disease among chronically ill patients. During the period 2001 to 2005, the national average for Medicare spending for the last two years of life was \$46,412. Thirteen states had spending levels above the national average. States with the highest spending consumed more than one and a half times the Medicare dollars spent by the lowest spending states. Three states—New Jersey, California, and New York—spent at a level that was more than 20% above the national average. At the opposite end of the

⁴⁹ Ibid.

⁵⁰ MedPAC, Report to Congress, 2008.

⁵¹ Ibid.

⁵² Ibid.

spectrum, three states—North Dakota, Iowa, and South Dakota—spent less than \$35,000 per person, more than 25% below the national average.⁵³

The Wennberg Study also found that geographic variation in spending on end-of-life care is largely due to differences in the availability of medical resources. Specifically, the greater the number of hospital beds and the number of physicians within a geographic region, the higher the rate of utilization and thus, costs. The study refers to this as “supply-sensitive” care. This geographic variation in utilization and costs is significant for the last six months of life. For example, a hospital length of stay varied from 6.1 days in the least supply-sensitive regions to 21.9 days for a hospital stay in the most supply sensitive regions.⁵⁴ The study also found that increased utilization of health care services did not necessarily translate into higher quality care or better health outcomes as measured from both the patient’s perspective (e.g., satisfaction, technical quality) and from the physician’s perspective (e.g., quality of communication among physicians, continuity of care).

These findings support results from a 2007 study that specifically analyzed the relationship between patient preferences and geographic variation in end-of-life care spending. In this study, the authors found no statistical relationship between patient preferences (such as use of a ventilator, medication, or other means to extend life) and regional variation in end-of-life care spending.⁵⁵

End-of-Life Care Laws and Ethics

The development of new technologies, and the associated prospect of longer, more protracted deaths, have focused some policy discussions on the topic of patients’ wishes. One result has been the development of laws regarding end-of-life care. Federal law generally defers to state law concerning health-care decision making, including end-of-life care decision making. Given the complexities in decision making surrounding medical interventions that have life-extending potential, all 50 states and the District of Columbia have passed laws to address end-of-life care issues. Specifically, state laws concerning end-of-life care include provisions for how end-of-life care decisions should be made when there is an advance directive that is signed prior to loss of competence and how decisions are to be made in the absence of an advance directive. However, state laws vary considerably regarding the terminology used, scope of decision making that can be addressed in the directive, restrictions on who may serve as a proxy, and the formalities required for making an advance directive.⁵⁶ Only one state, Oregon, has passed a law legalizing physician-assisted suicide.⁵⁷ The following describes the two types of advance directives (living

⁵³ Wennberg Study, 2008.

⁵⁴ Ibid.

⁵⁵ A. Barnato, M. Herndon, D. Anthony, et al., Are Regional Variations In End-of-Life Care Intensity Explained by Patient Preferences? *Medical Care*, vol. 45, no. 5 (May 2007).

⁵⁶ Charles P. Sabatino, “10 Legal Myths About Advance Medical Directives,” ABA Commission on Legal Problems for the Elderly, American Bar Association, Washington, DC, at <http://www.abanet.org/aging/publications/docs/10legalmythsarticle.pdf>.

⁵⁷ The Oregon Death With Dignity Act (DWDA, OR. REV. STAT. §§ 127.800-897) was enacted through a voter initiative process in November 1994. The DWDA went into effect in November 1997. For further information, see CRS Report RL33120, *Physician-Assisted Suicide and the Controlled Substances Act: Gonzales v. Oregon*, by (name redacted).

wills and health care powers of attorney) and federal Medicare and Medicaid laws concerning advance directives.

Advance Directives

An advance directive is a statement by a competent person indicating his or her wishes regarding medical treatment in the event of future incompetence.⁵⁸ In this context, incompetence means that a person cannot express his or her wishes. This could be caused by mental infirmity, unconsciousness, or the inability to communicate, for example. Advance directives may be used to address medical questions during any period of incompetence, including those periods associated with terminal illness.

There are two types of advance directives: living wills and health care powers of attorney (also referred to as a “durable power of attorney”). A living will can inform health care providers about the type of medical care that an individual wants provided or withheld. This may include any type of medical treatment, including a life-sustaining procedure. Living wills typically take effect when the patient cannot communicate his or her wishes for medical care (in extreme situations the patient may be permanently comatose) and diagnosed as close to death from a terminal illness. In general, once a physician receives a living will, he or she either must honor its instructions or transfer the patient to another physician who will honor them. A health care power of attorney is a document that identifies a health care proxy or decision maker for the patient. This document typically takes effect when a physician decides that a patient is unable to make a health decision.

Federal Laws Concerning Advance Directives

While federal law generally defers to state law concerning end-of-life care decision making, Congress has passed laws with respect to advance directives. These laws either affect health providers receiving federal funding or relate to military personnel and are described below.

Patient Self-Determination Act

In 1990, Congress passed the Patient Self-Determination Act (PSDA) as part of the Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508, Sections 4206 and 4751). The PSDA amended Titles XVIII (Medicare law) and XIX (Medicaid law) of the Social Security Act to require certain institutional providers and prepaid plans that participate in Medicare and/or Medicaid to follow specified policies and procedures in regard to advance directives.⁵⁹ The PSDA mandated states to develop written descriptions of relevant state law concerning advance directives that would be distributed by providers or organizations. Specifically, the law requires that these Medicare and

⁵⁸ A.E. Lazaroff and W.F. Orr, “Living Wills and Other Advance Directives,” *Clinics in Geriatric Medicine*, vol. 2, iss. 3 (August 1986), pp. 521-531.

⁵⁹ The Medicare participating providers that are subject to this law are hospitals, skilled nursing facilities, home health agencies, hospices, health maintenance organizations, competitive medical plans, and Medicare + Choice organizations (prepaid or eligible organizations) that participate in Medicare. The Medicaid participating providers that are subject to this law include hospitals, nursing facilities, home health agencies, personal care agencies, hospices, and managed care organizations.

Medicaid participating institutional providers or organizations maintain written policies and procedures with respect to:

- providing adult individuals with written information regarding their rights under state law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives, and provide individuals with written policies of the provider or organization respecting the implementation of those rights;
- documenting in the individual's medical record whether or not the individual has executed an advance directive;
- not conditioning the provision of care or otherwise discriminate against an individual based on whether or not they have executed an advance directive;
- ensuring compliance with requirements of state law respecting advance directives (for Medicare facilities, with respect to advance directives at facilities of the provider or organization); and
- providing education for staff and the community on issues concerning advance directives.

With respect to prepaid organizations, the Secretary of Health and Human Services (HHS) may not render payment unless the organization provides assurances, satisfactory to the Secretary, that they meet these requirements.

The PSDA also mandated that Medicare and Medicaid participating providers distribute information about advance directives according to the timing of certain medical or health-related events. Under the law, hospitals and nursing homes must provide this information about advance directives to individuals at the time of admission; home health agencies (and Medicaid-certified personal care agencies) must provide it in advance of the individual coming under the care of such agencies; hospice providers must provide this information at the time of the initial receipt of hospice care; and the prepaid health plans must provide it to individuals upon enrollment.

Medicare-certified providers that do not comply with these requirements may have payments withheld by the Secretary. Medicaid law does not contain a similar requirement regarding provider compliance concerning advance directives. Furthermore, state laws that allow for an objection on the basis of conscience for any health care provider or any agent of such provider which, as a matter of conscience, cannot implement an advance directive, shall supersede the PSDA.

Finally, the PSDA required HHS to undertake a public education campaign to inform individuals about their option to execute an advance directive and a patient's right to participate in and direct health care decisions. According to the law, this included developing or approving national educational materials that would be distributed by providers, assisting states in developing state-specific documents, and mailing information to Social Security recipients.

A 1995 GAO report described the PSDA implementation and effectiveness of advance directives in ensuring patient's self-determination.⁶⁰ The report found that institutional providers and HHS

⁶⁰ U.S. Government Accountability Office, *Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness is Uncertain*, GAO/HEHS-95-135, August 1995.

generally appear to be complying with most PSDA requirements. Limited data showed that most providers offered information to patients about executing an advance directive. However, GAO noted that problems may occur in documenting whether or not a patient has an advance directive. In addition, according to a report published by HHS in 2007, other than preparing a public information document (reprinted at 57 Fed. Reg. 8194, 8199, March 6, 1992), HHS has done relatively little in regard to the public information campaign.⁶¹

Other Federal Laws

Two other laws concerning advance directive and end-of-life care planning are the National Defense Authorization Act for Fiscal Year 1996 (P.L. 104-106) which established a federal advance directive for military personnel that explicitly preempts state law and the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275), signed into law on July 15, 2008. Among other things, the MIPPA provision adds “end-of-life planning” to the initial preventive physical exam that Medicare beneficiaries receive upon enrollment in Medicare. The law also defines “end-of-life planning” to mean verbal or written information regarding:

- an individual’s ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and
- whether or not the physician is willing to follow the individual’s wishes as expressed in an advance directive.

In a Senate Special Committee on Aging hearing on end-of-life care issues in the 110th Congress, written testimony from one witness stated that the end-of-life care planning provision in P.L. 110-275, “acknowledges the physician’s central role in prompting advance planning, although it is a minimal requirement that on its face can be complied with by handing patients another piece of paper with more information.”⁶²

Constitutional Status

While the right to refuse medical treatment has been addressed by legislation at the state level, even in those cases where no advance directive has been completed, or where the state law does not cover a particular medical circumstance, individuals or their guardians may still seek to make a medical decision which will ultimately cause the death of the patient. This was the litigation posture which led to the case of *Cruzan v. Missouri Department of Health*.⁶³

At the time of the litigation in *Cruzan*, Nancy Cruzan lay in a hospital bed in what is called a persistent vegetative state.⁶⁴ Although Nancy was able to take nutrition through spoon-feeding

⁶¹ U.S. Department of Health and Human Services, *Advance Directives and Advance Care Planning: Legal and Policy Issues*, by Charles P. Sabatino, American Bar Association, Commission on Law and Aging, October 2007.

⁶² Written testimony of Joseph D. O’Connor, in U.S. Congress, Senate Special Committee on Aging, Honoring Final Wishes: How to Respect Americans’ Choices at the End of Life, hearings, 110th Cong., 2nd sess., September 24, 2008.

⁶³ 497 U.S. 261 (1990).

⁶⁴ According to the Academy of Neurology, persistent vegetative state patients are permanently unconscious and devoid of thought, emotion and sensation. The state is described as a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles. Amicus Brief for Academy of Neurology at 3, *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1989)(No. 88-1503). It was estimated that 10,000 patients were being maintained in a persistent vegetative state in the United States. *Id.*

following an accident, it was determined that artificial nutrition and hydration were medically indicated. While the State of Missouri has a “Living Will” statute, it was not in effect at the time of Nancy’s accident, nor had Nancy written out such a will. The statute was relevant, however, because it specifically excluded the possibility that a patient’s Living Will could provide for the withdrawal of nutrition or hydration tubes. Thus, the Missouri legislature appeared to have made a decision that the withdrawal of nutrition and hydration was not within the realm of acceptable conduct even with the written consent of the patient.⁶⁵

The Cruzan case, because of its facts, presented two legal issues to the Supreme Court: first, whether Nancy Cruzan had the constitutional right, even absent legislative approval, to consent to the withdrawal of nutrition and hydration; second, whether this right could be exercised by a guardian, and furthermore what standard of proof would be required to show that such a course of action was the intent of the patient. The Supreme Court ultimately decided that the state may require clear and convincing evidence of her wishes, and as her guardians did not have sufficient proof, the nutrition and hydration could not be withdrawn.⁶⁶ While the Supreme Court did not technically decide the issue as to whether the Missouri court could have acted contrary to a clear and convincing expression of Nancy Cruzan to withdraw medical procedures, it did presume that such a right existed under the Fourteenth Amendment.⁶⁷ Thus, under Cruzan, an individual’s right to refuse medical treatment may be broader than the rights which are granted by state statutes.⁶⁸

Use of Advance Directives

The Cruzan case and other high profile cases involving an individual’s right to refuse or terminate medical treatment in the absence of an advance directive, such as Terry Schiavo, have generated considerable public awareness about the issue. However the likelihood that an individual has completed one is much lower. According to a recent survey by AARP, the vast majority of adult respondents age 35 and older reported that they had heard about advance directives (over 90%), but only 37% had established a health care proxy or durable power of attorney for health care and 36% had created a living will.⁶⁹ Survey respondents were more likely to have completed a last will and testament (45%) than report having completed an advance directive. When viewed by age of the respondent, those age 60 and older were more likely than younger adults to have an advance directive, such as a health care proxy (51%) or living will (47%). See **Table 4**. More than 6 in 10 older adults reported they had a trust or last will. The data also show that those who

⁶⁵ The Supreme Court of Missouri pointed out in its opinion how this case differed from many previous medical decision cases. Nancy was not dead, nor was she terminally ill, and she could have lived up to thirty years in her condition. Essentially, the decision, as stated by the court, was whether the hospital should be allowed to cause Nancy Cruzan to die by starvation or dehydration. The Supreme Court of Missouri considered the case as one of first impression for Missouri, and declined to allow the hospital to withdraw nutrition and hydration. *Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1989)(en banc).

⁶⁶ The Court found that it was not constitutionally required that guardians or family be allowed to effectuate such a decision. *Cruzan*, 497 U.S. at 284. Rather, the Court determined that not only could a state require that a patient’s own personal wishes be examined, but that absent clear and convincing evidence of such wishes, a state could decline to allow withdrawal of treatment.

⁶⁷ See also *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997)(“We have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment”).

⁶⁸ For a detailed discussion of the Cruzan case, see CRS Report 97-244, *The "Right to Die": Constitutional and Statutory Analysis*, by (name redacted).

⁶⁹ AARP, *AARP Bulletin Poll 'Getting Ready to Go' Executive Summary*, AARP, Washington, DC, January 2008.

reported their health status as excellent or very good were most likely to have heard of and completed an advance directive compared to those in good health and poor health.

Table 4. Likelihood of Completing Advance Directives or Last Will, by Age Group and Health Status

	Health Care Proxy (%)	Living Will (%)	Trust or Last Will and Testament (%)
Age Group			
35 to 49 years	24	25	32
50 to 59 years	39	36	44
60+ years	51	47	62
Health Status			
Excellent	40	36	52
Very Good	43	44	54
Good	30	28	34
Fair/Poor	35	32	41

Source: AARP, AARP Bulletin Poll ‘Getting Ready to Go’ Executive Summary, AARP, Washington, DC, January, 2008.

Notes: Respondents were asked whether or not they had heard about and completed each type of document: (1) health care proxy, (2) living will, (3) trust or last will and testament. Therefore table rows do not sum to 100% due to multiple responses.

Implementing Advance Directives

If all patients had advance directives, some of the issues associated with end-of-life care might be resolved. However, the boundaries of a seemingly clear-cut presumption to follow individuals’ treatment wishes can become blurred. For example, a patient may be incapable of creating an advance directive because he or she is unconscious, too young, suffering from dementia, or for some other reason. An emergency provider might not know that a patient has an advance directive. A patient’s advance directive may not be available in a facility that the patient does not usually visit. A patient may desire treatment that will shorten his or her life, such as the administration of large amounts of pain medicine, which may not conform with local laws and institutional policies. A patient may want assisted suicide, which is not permissible in most states. Family members may threaten or pursue legal action against health providers for decisions with which family members disagree—even when those decisions accord with patient wishes. In addition, patients may change their preferences after executing an advance directive, which might not be respected unless the changes are reflected in documentation. Each of these possibilities can create challenges for the health delivery system and provision of end-of-life care.

Ethics of Care at the End of Life

The topic of end-of-life care has been discussed in the medical ethics arena for years. The issue has caused debates about the appropriate use of technology and other treatments to prolong life, circumstances in which patients may forego life-sustaining treatments or hasten their own deaths,

and how our cultural notions of death perpetuate each of these. The following provides information about the role of ethics committees in helping reach resolutions.

In health care institutions, ethics committees are groups of people who may be consulted when ethically difficult situations arise, including those that may emerge at the end of life. Although institutions are not required by federal law to have ethics committees, some of the Joint Commission's current requirements are often satisfied by maintaining an ethics committee.⁷⁰ The specifics of the committee's composition, processes and responsibilities are neither federally mandated nor uniform. However, there are some norms.

Ethics committees' membership typically consists of some combination of health care providers, clergy, ethicists, lay persons, and lawyers. Participation in a committee is not a paid activity, except that health care employees may serve on a committee as one component of their employment. Ethics committee consultation may be requested by health professionals, patients and/or family members. It may occur when a requester wants input into a difficult decision, or when there is some disagreement among interested parties about the appropriate course of action. The result of the consultation is a non-binding recommendation.

One study that estimated the costs of ethics consultations among adult patients in the intensive care unit (ICU) with respect to the use of "nonbeneficial treatments" found that these consultations were associated with reductions in hospital days and treatment costs among those who did not survive to discharge.⁷¹ The authors conclude that such consultations may resolve conflicts that would have prolonged treatment among these patients and therefore may allow physicians to focus on palliative or comfort care.

Studies indicate that consultation services are widespread, but many doctors hesitate to ask for ethics help.⁷² In addition, questions about ethicists' training and performance persist. Ethics committee training, if it does occur, typically includes some introduction to health care facility practices, the ethics committees' role, an overview of some relevant laws and regulations, and may include some basic training in medical ethics. For example, participants might learn about several ethical principles that can be used to characterize a range of issues they will face:⁷³

- Autonomy: respect patients' wishes.
- Beneficence: act to benefit patients.
- Nonmaleficence: do not harm patients.
- Justice: distribute the risks and benefits equally.

⁷⁰ The Joint Commission is an independent, not-for-profit organization that accredits and certifies more than 15,000 health care organizations and programs in the United States, see <http://www.jointcommission.org/AboutUs/brand.htm>; University of Buffalo, "Ethics Committees—Functions And Models," Ethics Committee Core Curriculum," January 25, 2008, at <http://wings.buffalo.edu/faculty/research/bioethics/man-fun.html>.

⁷¹ Todd Gilmer, Lawrence J. Schneiderman, Holly Teetzel, et al., "The Costs Of Nonbeneficial Treatment In The Intensive Care Setting," *Health Affairs*, vol. 24, no. 4 (July/August 2005), pp. 961-971.

⁷² Kevin B. O'Reilly, "Willing, but waiting: Hospital ethics committees," *Amdnews.com*, January 28, 2008, at <http://www.ama-assn.org/amednews/2008/01/28/prsa0128.htm>.

⁷³ See, for example, Tom Beauchamp and James Childress, *The Principles of Biomedical Ethics*, 4th ed. (New York, NY: Oxford University Press, 1994).

The topics of training requirements for ethics committee members, and of accreditation requirements for ethics committees have been widely debated. While each may be desirable, the time commitment of unpaid volunteers, and the cost to the health system may prove prohibitive.

Quality of End-of-Life Care

End-of-life care to individuals, where death is a certain or predictable outcome, is a critical component of the continuum of health care services. Due to its timing, duration, and intensity, end-of-life care presents numerous challenges and opportunities for quality measurement, assessment, and improvement. Because end-of-life care can be palliative, and not curative, assessments of quality are often based on family and patient satisfaction. Studies have documented several factors which are associated with perceptions of higher quality care by patients and families. These include expressions of patients' wishes, discussions of families' spiritual needs, documentation of a living will, and family presence at the time of death.^{74,75}

A number of initiatives are currently underway in the private and public sectors to improve the quality of care individuals receive at the end of life, and specifically the quality of palliative and hospice care. These initiatives broadly cover efforts to develop and disseminate consensus-based quality of care measures for hospice and palliative care; to return more rights to the individual patient with regard to his or her own care; to create changes in and alignment of payment policy to improve quality of end-of-life care; and to drive evidence-based change in the provision of end-of-life care.

The Center for Medicare and Medicaid Services (CMS) has undertaken efforts toward improving the quality of care provided at the end of life. Specifically, these include updating Medicare conditions of participation for hospice providers to include quality improvement activities and incorporating an advance plan measure into the Physician Quality Reporting Initiative (PQRI). These efforts are described in more detail below.

Medicare Hospice Quality Rule

In June 2008, CMS released final guidelines outlining updated conditions of participation for hospice providers. The new rule which takes effect on December 2, 2008, reflects a desire to empower patients, requiring that patients be more actively involved in developing their care plan. This includes allowing a patient to refuse treatment, to choose his/her own physician, and to have access to pain medications. The rule also specifies a schedule for which patient evaluations and follow-up assessments must be made. More importantly, the rule also requires hospice providers to assess their own quality performance, to document improvement in areas of deficiency, and to directly involve physicians providing care in these activities. Advocates hope that this information will eventually become available to the public in order to aid patients as they choose a facility, although for now the information will only be available to the hospice provider and to CMS.

⁷⁴ Cynthia J. Gries, J. Randall Curtis, Richard J. Wall, et al., "Family Member Satisfaction with End-of-Life Decision Making in the ICU," *Chest*, vol. 133, no. 3 (March 2008), pp. 704-712.

⁷⁵ B.J. Glavan, R.A. Engelberg, L. Downey, et al., "Using the medical record to evaluate the quality of end-of-life care in the intensive care unit," *Critical Care Medicine*, vol. 36, no.4 (April 2008), pp. 1138-1146.

Physician Quality Reporting Initiative Advance Plan Measure

As directed by Congress, and as part of efforts to move toward value-driven health care, the Medicare program has implemented a quality reporting program for physicians. What began as the Physician Voluntary Reporting Program (PVRP) in early 2006 has evolved into the Physician Quality Reporting Initiative (PQRI). The PVRP was not mandated by statute but allowed physicians to voluntarily report quality data to CMS in order to establish a reporting infrastructure and address any reporting problems. There were no financial incentives tied to this early program. The PQRI, in contrast, will provide physicians with an annual bonus payment for 2009 of 2.0% of eligible Medicare charges for meeting specific quality measure reporting requirements. In July of 2007, CMS officially began collecting this quality data from Medicare participating physicians.

The PQRI program is not specific to end-of-life care, but because end-of-life care has been identified as an important area of focus for quality improvement efforts, the program does utilize several geriatrics measures, including one measure which specifically addresses advance care plans. This measure aims to assess whether a patient has an advance care plan or surrogate decision maker documented in his or her medical record. If an advance care plan or surrogate decision maker is not documented, the measure prompts physicians to query the patient as to his or her reasons for this and to document that a discussion took place but it is the patient's option not to provide an advance care plan or document a surrogate decision maker. The exact language of the measure is as follows:

Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan in the medical record.⁷⁶

National Quality Initiatives

In addition to activity at CMS, important work on the development of clinical practice guidelines in palliative and hospice care was undertaken by the National Consensus Project for Quality Palliative Care (NCP) and by the National Quality Forum (NQF). These efforts culminated in two seminal documents which set forth clinical guidelines in this area: "A National Framework and Preferred Practices for Palliative and Hospice Care Quality"⁷⁷ and "Clinical Practice Guidelines for Quality Palliative Care."⁷⁸

National Consensus Project for Quality Palliative Care (NCP)

The Hospice and Palliative Care Coalition (HPPC), representing three national palliative care organizations,⁷⁹ governs the National Consensus Project for Quality Palliative Care (NCP). The

⁷⁶ Centers for Medicare and Medicaid Services, "2009 PQRI Measures List," at <http://www.cms.hhs.gov/PQRI/Downloads/2009PQRIMeasuresList.pdf>.

⁷⁷ National Quality Forum, "A National Framework and Preferred Practices for Palliative and Hospice Care Quality," 2006, abstract and executive summary available at <http://www.qualityforum.org/publications/reports/palliative.asp>.

⁷⁸ National Consensus Project for Quality Palliative Care, "Clinical Practice Guidelines for Quality Palliative Care," May 2004, at http://www.nationalconsensusproject.org/Guidelines_Download.asp.

⁷⁹ The HPPC is represented by the Hospice and Palliative Nurses Association (HPNA), American Academy of Hospice and Palliative Medicine (AAHP), and the National Hospice and Palliative Care Organization (NHPCO).

original goal of the NCP was to develop clinical practice guidelines through a consensus, evidence-based review process. The project is currently focused on the education and dissemination of these guidelines to health care professionals and the public. It is anticipated that these efforts will lead to the endorsement and voluntary implementation of NCP's clinical guidelines among health professionals. These clinical practice guidelines were developed with the following goals:

- to facilitate the development and continuing improvement of clinical palliative care programs;
- to establish uniformly accepted definitions of the essential elements in palliative care;
- to establish national goals for access to quality palliative care;
- to foster performance measurement and quality improvement initiatives in palliative care services; and
- to foster continuity of palliative care across settings (home, residential care, hospital, hospice).⁸⁰

National Quality Forum's National Framework and Preferred Practices for Palliative and Hospice Care

In 2005, the National Quality Forum (NQF) initiated a project whose dual purposes were to develop and endorse a framework for providing quality palliative and hospice care and provide a set of recommended practices for the delivery of this care. The work of NQF is similar to NCP, as it is largely based on NCP's guidelines and also attempts to formalize the concept of palliative care. However, NQF's work differs from NCP as it was carried out with the intention of serving as a basis for the future development of quality measures that will address palliative care standards. These standards, in turn, may have an impact in areas such as reimbursement, regulation, and accreditation.

Issues for Congress

As the nation prepares for an aging population and likely increase in demand for high quality end-of-life care services among the elderly, Congress may face a decision whether to modify or expand the role of the federal government in providing support to individuals and families to assist with end-of-life care. Some policy makers may favor enhancing federal support for research on end-of-life care practices or programs that provide end-of-life care services. In doing so, the federal government would devote additional funding to new or existing programs, implying increasingly difficult tradeoffs between end-of-life care services and supports and federal programs that benefit other populations.

Alternatively, some policy makers may feel that additional federal support to states regarding end-of-life care issues is warranted, and that the federal government can best serve individuals

⁸⁰ National Consensus Project for Quality Palliative Care, at http://www.nationalconsensusproject.org/Guidelines_Usage.asp.

and families by providing technical assistance in care planning and service delivery or federal funding for end-of-life care services. Still others may believe the federal government has a limited responsibility in assisting individuals and families regarding such a private and personal matter as the provision of medical and health care at the end of life. Thus, Congress may decide that no additional federal assistance can be made available. In this case, federal policy makers may want to evaluate how best to spend existing funds.

This section briefly describes policies that would expand the federal government's role in addressing the issue of end-of-life care and have been the subject of discussion among federal policy makers and other interested stakeholders. They are organized into the following topics: training for health professionals, end-of-life care planning, support to family caregivers, and other policy issues.

Education and Training for Health Professionals

Policymakers have suggested that greater emphasis should be placed on educating and training health professionals including physicians, nurses, and social workers about palliative care, pain and symptom management, and end-of-life care decision making and supportive services. Some suggest that training for health professionals should not only focus on medical practices to improve pain and symptom management, but include communication skills that address discussion of sensitive issues surrounding end-of-life decision making with patients and their families. Observers note that with greater training and education, physicians may be more comfortable discussing death, end-of-life care expectations, and patient preferences for how and where they would like to receive care.

Policymakers have proposed various palliative care training initiatives for health professionals. Some suggest new federal grant programs to establish or expand upon existing palliative care and symptom management programs. Others would implement grants programs to improve the quality of graduate and postgraduate training or provide continuing professional education for physicians, nurses, and other health care providers in palliative care and symptom management. Another proposal would establish grants programs at the National Institutes of Health (NIH) for research on palliative care and other end-of-life care topics. Other policy recommendations include providing incentives under general medical education (GME) funding to support training in palliative care and other related fellowship programs (e.g., geriatrics, internal medicine, pediatrics, family practice); providing education and training for mid-career nursing staff in long-term care settings; and training and education for nursing home administrators.⁸¹

End-of-Life Care Planning

Some policymakers have pointed toward the need to educate consumers about establishing advance directives. While surveys indicate that most adults are aware of advance directives, observers suggest that there may be institutional and psychological barriers that prevent individuals from executing an advance directive. For example, individuals may falsely believe that these documents must be drafted by a lawyer or that the decisions made in an advance directive are not irreversible or easily changed. Furthermore, doctors may not be informed about

⁸¹ Terrie Wetle, Joan Teno, Renee Shield, et al., "End of Life in Nursing Homes: Experiences and Policy Recommendations," AARP Public Policy Institute, Washington, DC, November 2004.

the content of a patient's advance directive. Currently, Medicare and Medicaid law only require certain providers to indicate whether or not the patient has an advance directive in their medical record. Finally, the content of advance directives are subject to state law or regulation. While some states recognize an approved advance directive from another state, other states do not have similar laws or regulations. Policymakers have also suggested developing public information campaigns to better inform individuals about end-of-life care planning and decision making.⁸²

Physicians providing curative treatment to patients diagnosed with a severe illness, such as cancer, may be reluctant to discuss end-of-life care planning with their patients viewing the nature of this conversation as a sign of professional failure. One mechanism for prompting people to consider and articulate their wishes regarding end-of-life care might be to require conversations about end-of-life care decision making between patients and health professionals. In turn, this may make such conversations more pervasive in society, removing stigma as the conversations become commonplace. One longitudinal study of patients with advanced cancer and their caregivers found that end-of-life discussions with physicians resulted in the receipt of less aggressive medical care near death and earlier hospice referrals.⁸³ In addition, the study found that less aggressive medical care and earlier hospice referrals were associated with better patient quality of life near death.

Policymakers have proposed federal legislation that would address several issues, including enhanced communication between health professionals and patients regarding advance directives; inclusion of the content of a patient's advance directive in their medical record; and state portability of advance directives. Others have suggested that each patient complete a standardized document designed to express the patient's treatment preferences, but not supplant state end-of-life care forms. Some have identified the issue of improved consumer information through a national public education campaign on end-of-life care decision making or an information clearinghouse, such as a 24-hour hotline or web-site, that would provide consumers information about advance directives and available hospice care services. Another proposal would require the Department of Health and Human Services (HHS) develop a web-site to provide information and to store and access such advance directives.

Support to Family Caregivers

Family members caring for a loved one needing end-of-life care may need services that can help them with their caregiving responsibilities as well as emotional support with their loved one's death. A 2007 GAO study identified family caregiver support and communication among individuals, families, and staff as key components of end-of-life care programs in a four state analysis (Arizona, Florida, Oregon, and Wisconsin).⁸⁴ GAO reports that the state programs identified provide family and caregiver support through services such as respite care, which helps to temporarily alleviate family caregiver's responsibilities. These state programs also provided bereavement support for family members. However, GAO noted that some providers described

⁸² Ibid.

⁸³ Alexi Wright, Bahohui Zhang, Alaka Ray, et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment," *Journal of the American Medical Association*, vol. 300, no. 14 (October 8, 2008), pp. 1665-1673.

⁸⁴ U.S. Government Accountability Office, *End-of-Life Care: Key Components Provided by Programs in Four States*, GAO-08-66, December 2007.

difficulties targeting caregiver support services to rural residents due to travel distances and fewer community based options.⁸⁵

To assist family caregivers to older adults, the federal government has established the National Family Caregiver Support Program (NFCSP). Administered by the HHS Administration on Aging, the NFCSP is a state formula grant program that provides funding for direct services to family caregivers. While the NFCSP is not targeted at caregivers assisting a dying family member, NFCSP services include individual counseling, support groups, and respite care among other services that may assist them.⁸⁶ Several policymakers have suggested enhancing funding for this program to assist with greater demand from caregivers. Funding for the NFCSP in FY2008 is \$153.4 million. Other policy proposals to assist family caregivers include greater workplace accommodations for employed caregivers who may need time out of the workforce to care for an ill or dying family member as well as tax credits to family caregivers.⁸⁷

Other Policy Issues

Other policy issues to improve the delivery of end-of-life care services have been raised by different stakeholders. These policy issues cover a range of topic areas from funding for research and best practices to provider reimbursement and quality of care. Some of these policy issues include, but are not limited to:

- developing new research and knowledge for improved practices, including federal funding for educational centers or centers of excellence focused on symptom management and end-of-life care;
- modifying reimbursement policy to create incentives for physician communication about end-of-life care decision making;
- permitting Medicare hospice beneficiaries to receive curative care in addition to hospice benefits;
- providing opportunities for the integration of Medicare and Medicaid services in order to coordinate care across acute and long-term care settings;
- examining and addressing quality of care at the end of life in various settings (e.g., hospital, nursing home, private home);
- developing general requirements, committee training, and accreditation for medical ethics committees; and
- enforcing prescription drug abuse without limiting physicians' abilities to prescribe pain killing drugs.⁸⁸

⁸⁵ Ibid.

⁸⁶ For further information on the NFCSP, see http://www.aoa.gov/prof/aoaprogram/caregiver/overview/exec_summary.aspx.

⁸⁷ For further information on family caregiving to the older population see, CRS Report RL34123, *Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress*, by (name redacted).

⁸⁸ Terrie Wetle, Joan Teno, Renee Shield, et al., "End of Life in Nursing Homes: Experiences and Policy Recommendations," AARP Public Policy Institute, Washington, DC, November 2004; Lisa R. Shugarman, Karl Lorenz, Joanne Lynn, "End-of-Life Care: An Agenda for Policy Improvement," *Clinics in Geriatric Medicine*, vol. 21 (2005), pp. 255-272.

Conclusion

The provision of high quality end-of-life care is a complex issue for policymakers. Individuals diagnosed with a terminal illness have different preferences for treatment, including differing cultural and spiritual attitudes related to death and dying and availability of family or social supports to assist them. Where death is predictable, end-of-life care may be delivered and managed by a team of health professionals, resulting in the necessity for care coordination and enhanced communication between health providers and among providers, individuals, and families. The provision of end-of-life care services also involves multiple entities, including the services and support needs not only of patients, but of family members and friends. As a result of this complexity, public policy that aims to improve the quality of end-of-life care may need to take a multifaceted approach by addressing a range of issues such as those mentioned above – training for health professionals, end-of-life care planning, and support to family caregivers. In addition, further research on the costs, delivery of services, and quality measures related to end-of-life care may assist policymakers in improving care at the end of life.

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