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END-OF-LIFE CARE IN THE UNITED STATES

This chapter discusses the history of our approach to death and dying in the United States of America. We will discuss the trend toward life-sustaining treatment in the U.S., then the development in the 1970s of the hospice philosophy, which encouraged palliative rather than curative care in terminal illness. We will discuss implications for health care costs, Medicare and Medicaid coverage of hospice, with resulting advantages and disadvantages in policy issues and barriers for utilization, including by some ethnic and racial communities. We will discuss the development of the field of palliative care and ethical issues surrounding passive and active euthanasia or physician-assisted suicide. We will discuss advance directives as a way to clarify patient wishes and uphold patient self-determination. We will conclude with a discussion of policy that covers some recommendations for policy change in the field of hospice and end-of-life care.

FROM DYING AT HOME TO DYING IN THE HOSPITAL

During the first half of the twentieth century in the United States, people typically died at home, cared for by family members. The death of loved ones was a familiar experience, not one to be kept out of sight and awareness. Death was expected as a natural part of life, and religious beliefs about the nature of the afterlife helped many cope with their own deaths or those of loved ones. End-of-life care decisions were made by physicians who had a long-standing and close relationship with their patients (Harper 2011).

Medical advances in the second half of the century, however, made us think life could be prolonged indefinitely. The major infectious diseases

could be controlled through medication, and surgical techniques were developed to control other life-threatening illnesses. Patients whose hearts stopped beating could be resuscitated. The well-loved family doctor gave way to doctors unknown to the patient providing aggressive end-of-life care in the hospital (Reith and Payne 2009; Silverman 2004).

The result of these advances was to increase the lifespan from forty-seven years in 1900 to seventy-four years for men and seventy-nine for women in 2004 (Social Security Online 2004). Religious beliefs gave way within the dominant cultural group to the belief that doctors held the key to life and death. At the same time, families felt morally obligated to access all available medical treatments, regardless of the likelihood of effectiveness (Blacker 2004; Buckey and Abell 2010; Forbes, Bern-Klug, and Gessert 2000) and regardless of the cost (Arons 2004).

Thus, today, only 38 percent of deaths occur in hospice (Jennings et al. 2003), with many others occurring in hospitals and nursing homes rather than at home (*Quality of Life Matters* 2004; Silverman 2004), and with the patient surrounded by technology instead of by loved ones. Regardless of the likelihood that patients will recover from life-threatening conditions, physicians attempt to save and prolong their lives through full use of technology or *life-sustaining treatment*. Even with a *terminal prognosis* (a prediction that the patient will not recover from the illness, but will die from it within six months), they often do not provide *palliative care* (treatment with the goal of comfort and control of symptoms rather than cure) until death is imminent (Blacker 2004; Silverman 2004).

QUALITY OF LIFE IN END-OF-LIFE CARE

This prolonged life has not necessarily been experienced as a good quality of life, however, but has resulted in increased numbers of people living in a serious, debilitated state. Many of these are without adequate pain control, wish for but do not receive physician contact, and do not receive adequate emotional support (Peres 2011; Silverman 2004). In addition, patients may be treated with a lack of respect (*Quality of Life Matters* 2004). Loss of dignity during the dying process has been linked with psychological and symptom distress, heightened dependency needs, and loss of the will to live (Chochinov et al. 2002).

Patients who are resuscitated may have to live on life support, including ventilators to allow them to breathe and artificial nutrition and hydration to

allow them to gain nourishment. The continued life may be spent undergoing surgery and painful treatments that have little chance of improving the patient's condition. At the same time, patients who do not improve may be regarded as failures and avoided by health care professionals (Silverman 2004). In addition, physicians may fail to inform patients of their prognosis and all options for curative and palliative care (Arons 2004). Without knowledge of one's prognosis and treatment options, a patient is unable to exercise informed consent. This in turn compromises patient self-determination. For these reasons, a number of authors consider end-of-life care in the U.S. today to be inadequate (Kramer, Hovland-Scafe, and Pacourek 2003).

Health care costs have also been a major social problem in the U.S. for decades. The next section will focus on the implications of end-of-life care for the cost of health care in America.

IMPLICATIONS FOR HEALTH CARE COSTS

Costs of this futile treatment have detrimental affects on individuals, families, and our nation (Baily 2011). During the dying process, many families lose most or all of their savings (Reith and Payne 2009). One-third of all health care dollars in the United States are spent on medical care in the last two years of life (Goldberg and Scharlin 2011). Skyrocketing costs have made it difficult for U.S. companies to compete on the world market, due to translation of employee health insurance expenses into product prices. The impact on our nation has led some authors to argue that patient self-determination, in terms of choosing the option of curative care, is overemphasized to the detriment of the common good (Baily 2011). Managed care health insurance companies have changed the face of medicine when physicians could not, increasingly refusing to cover "futile care." The next section discusses an alternative perspective, the hospice philosophy.

RISE OF THE HOSPICE MOVEMENT

DEVELOPMENT OF THE HOSPICE PHILOSOPHY

A movement founded in the 1960s in England by Dame Cicely Saunders, and continuing in the 1970s in the United States through the work of

Elisabeth Kubler-Ross, began to advance a new set of values. Saunders founded St. Christopher's Hospice in London in 1967 (www.stchristophers.org.uk). Trained as a social worker, nurse, and physician, she promoted a holistic model of care provided by an interdisciplinary team.

This treatment was focused not on *curative treatment*, with the goal of curing the patient's disease, but on *palliative care*, aimed at promoting quality of life during death and dying: "You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die" (Dame Cicely Saunders, quoted by AScribe Newswire 2005). The focus was on *palliative care*, the treatment of symptoms rather than the disease.

Death with dignity and patient self-determination are cornerstones of this new perspective. In the face of terminal illness, the patient chooses comfort rather than cure, palliative care or palliation of symptoms rather than curative care aimed at eradication of the disease. The goal is to focus on enjoying one's remaining days and to make legal, emotional, and spiritual preparations for death. Death is accepted as a natural part of life. In the U.S., hospice philosophy is oriented toward death in the home, surrounded by loved ones and an environment arranged according to the patient's wishes. The interdisciplinary hospice team provides holistic care that addresses the physical, psychological, social, and spiritual needs of the patient and significant others (Black 2007). The focus is on advocating for the patient's individual preferences, despite family or physician opinions to the contrary. The patient has rights to information about her prognosis and to make decisions about end-of-life care based on this information. Until her death at St. Christopher's Hospice in 2005, Saunders promoted these values, which came to be known as the hospice philosophy, a new perspective that led to significant changes in end-of-life care around the world.

DEFINITIONS   The National Association of Social Workers (NASW 2011) has provided some definitions that are helpful in distinguishing between several types of care in terminal illness. *End-of-life care* is defined by NASW as "multidimensional assessment and interventions provided to assist individuals and their families as they approach end of life" (p. 4). End-of-life care decisions vary greatly and can include curative care or palliative care, with or without advance directives. Decisions may be made by patients or left to family members and are influenced by psychosocial, spiritual, and cultural factors. End-of-life care may include hospice or palliative care.

Palliative care is defined by NASW (2011) as an approach that focuses on quality of life through prevention and relief of suffering on physical, psychosocial, and spiritual levels. Palliative care offers relief of symptoms when no cure is possible. It may be offered in chronic illness as well as in terminal illness. *Hospice* is a form of palliative care that is offered specifically in terminal illness (Reith and Payne 2009).

DEVELOPMENT OF HOSPICE IN THE UNITED STATES

Shortly after the founding of St. Christopher's, Elisabeth Kubler-Ross, a physician critical of the inhumane treatment of dying patients, became a leader of the hospice movement in the U.S. Her groundbreaking book, *On Death and Dying* (1970), became a best seller and influenced public opinion in the U.S. and globally.

The first U.S. hospice was established in 1971, in Branford, Connecticut, by a team from Yale University consisting of a nurse, two pediatricians, and a chaplain. In 1972 Kubler-Ross testified in front of the Senate, the first of a series of efforts to promote the hospice concept.

Also in 1972, the American Hospital Association developed the "Patient Bill of Rights." This statement provided for the patient's right to make choices relating to types of treatment received, including the right to refuse treatment, to refuse life-sustaining measures, and to terminate treatment. It also provided for the patient's right to all comfort measures. Finally, the patient had the right to know the truth of his condition.

Because of this model, hospice proponents were able to show that home care was less expensive than institutional care, leading to Medicare reimbursement for hospice under the Tax Equity and Fiscal Responsibility Act in 1982 (Harper 2011). Medicare coverage has had a major influence on the care of the dying, as 85 percent of people who die in the U.S. each year are covered by Medicare (Werth and Blevins 2002).

The Medicare Hospice Benefit transformed hospice philosophy into federal regulation, requiring an interdisciplinary approach that includes physician, nursing, home health aide, social work, and spiritual care. The benefit covers prescription medication, medical supplies and equipment, short-term care in an inpatient setting (e.g., for pain and symptom control or caregiver respite), and bereavement counseling for significant others after the patient's death. For each day the patient is enrolled under the Medicare Hospice Benefit, the hospice receives a per diem amount.

In order to receive the benefit, a patient has to be terminally ill, with a physician certifying a prognosis of six months or less. A patient can cancel enrollment in hospice any time and then reenter if she still has a six-month prognosis. A patient can remain in hospice longer than six months if the certifying physician still believes that she has a prognosis of less than six months. Any diagnosis is eligible, although cancer has been the primary diagnosis of patients served, due to the greater ability to predict the course of illness of a cancer diagnosis.

The focus of the Medicare Hospice Benefit was to save money, and thus eligibility limitations are imposed. While enrolled in hospice, the patient must agree to forego curative or life-sustaining treatments and be cared for at home by a significant other.

In 1986 states were given the option to include a hospice benefit within Medicaid programs. Thus hospice care was now available for nursing home residents. This had a major impact, since 35 percent of older adults use nursing home care in the last year of life (Werth and Blevins 2002). Medicaid provides health and long-term care to individuals with low incomes (including those who have been impoverished by health care costs). Not all states cover hospice under Medicaid though. In 1995 the military began to offer hospice benefits to family members.

The hospice movement has continued to grow, with the National Hospice and Palliative Care Organization (NHPCO) reporting a yearly increase in the number of operating hospices nationwide. In 2008 there were more than 4,850 hospices in the U.S. that served 1.45 million people. It is estimated that 38.5 percent of deaths occur within hospice care (NHPCO 2009). The next section will discuss standards for end-of-life care.

PROFESSIONAL STANDARDS FOR END-OF-LIFE MEDICAL CARE

Care that addresses quality of life is now increasingly recognized as an ethical obligation of health care providers, and several expert-developed descriptions of such care exist. In 2001 the Institute of Medicine described quality end-of-life care in terms that reflected the hospice philosophy. These parameters for a good death include a death that is free from avoidable distress and suffering for patients, families, and caregivers, in general accord with patients' and families' wishes and reasonably consistent with clinical,

cultural, and ethical standards (Roff 2001). Similarly, in 2003 Robert Wood Johnson developed quality indicators for end-of-life care that reflected a hospice perspective, including emotional, spiritual, and practical support and adequate symptom control.

Singer and colleagues (Singer, Martin, and Kelner 1999) have also contributed in this area by developing a framework based on the perspectives of patients and families. They have identified five domains important to "quality end-of-life care": receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. Farber, Egnew, and Farber (2004) add to this discussion the alternative term *respectful death*, in which a caregiver's perception of what constitutes a "good death" is not imposed upon the patient, but rather the patient's agenda and individual experience is respected. This perspective on care is reflected in the hospice model of care, discussed in the following section.

HOSPICE MODEL OF CARE

Patients are admitted to a hospice program when medical science can offer no cure to them and, in all likelihood, they are expected to die within six months. The patient is aware of the prognosis at admission and agrees to a program of palliative care aimed toward comfort rather than cure. The goal of patient comfort is taken seriously, and hospice staff is highly skilled in symptom control. Enrollment in a hospice program does not mean that the patient will not receive treatment needed for comfort; chemotherapy and radiation may even be used to control pain, and many other treatments are available to control the symptoms of terminally ill patients. However, treatment is not aimed at curing the terminal illness, since it has already been determined that the illness cannot be cured through medical science.

In the United States most hospice care can be, and is, provided in the patient's home. In addition, some hospices have inpatient units or contract for facilities that serve patients who have no primary caregiver who can care for them at home. Hospice services are increasingly provided in nursing homes as well (Reith and Payne 2009), but are underutilized (Chapin et al. 2007). The hospice program provides medical, psychosocial, and spiritual care for the patient through an interdisciplinary, holistic approach. Members who

serve on the interdisciplinary team and develop treatment plans for patients include social workers, nurses, home health aides, clergy, physicians, volunteers, administrators, and other professionals as needed. Although each member has an area of expertise, all members address all aspects of care in contacts with the patient and family.

The origins of hospice in a volunteer grassroots movement are still felt today. Hospices provide volunteers who assist in many aspects of hospice care and administration. Volunteers sit with patients while family caregivers take a break or attend other responsibilities, volunteers run errands, provide transportation, bereavement counseling, or clerical duties at the hospice, among many other contributions. The tradition of serving patients without charge is still honored as well; many hospices will serve patients regardless of ability to pay.

In this section we have described the way hospice care is delivered. The next section will discuss evidence regarding the outcomes of patients and families who receive these services.

HOSPICE OUTCOMES

Research has indicated that terminally ill patients served by hospice experience more positive outcomes than those receiving other types of care at the end of life. In comparisons with patients being actively treated for cancer (Harper 2011), hospice patients had a lower incidence of anxiety and grief. It may be theorized that the psychosocial care these patients received helped to allay these feelings. In another study Teno and colleagues (2004) found that family members of patients receiving home hospice services were more satisfied than those dying in an institutional setting or with home health services. Nonhospice patients had high levels of unmet needs for symptom control, physician communication, emotional support, and being treated with respect by health care professionals (Teno et al. 2004). Similar findings were obtained in a comparison of terminally ill African American patients who did or did not receive hospice services (Reese et al. 2004). Other studies have found that in nursing homes hospice patients received better pain control than nonhospice patients and often live longer than those with the same diagnosis who did not choose hospice (Reith and Payne 2009). The next section provides an overview of passive euthanasia, active euthanasia, and assisted suicide.

EUTHANASIA AND ASSISTED SUICIDE

PASSIVE EUTHANASIA

Passive euthanasia, which characterizes hospice care in states in which assisted suicide is illegal, involves *withholding* curative or life-sustaining treatment in the case of terminal illness. In passive euthanasia health care providers allow death to occur naturally, without providing life-sustaining treatment or "heroic efforts" to prolong the patient's life.

Passive euthanasia also includes *withdrawing* care, in the case of a patient receiving life support but without hope of improved quality of life. Courts and philosophers don't distinguish between withholding or withdrawing life-sustaining treatment, but withdrawing care is far more controversial, as landmark court cases indicate. Withdrawal from treatment, such as removal of life support, is considered by many citizens as more aggressive than the withholding of treatment, on a par with assisted suicide (Altilio 2011).

The cases of twenty-one-year-old Karen Ann Quinlan in 1975 and Nancy Cruzan in 1983 promoted public acceptance of passive euthanasia. Ms. Quinlan lost consciousness after overdosing on alcohol and tranquilizers. Physicians resuscitated her, but she suffered brain damage and lapsed into a "persistent vegetative state." Her family fought a legal battle, and finally won, for the right to remove her from life support.

Nancy Cruzan entered a persistent vegetative state after an auto accident and was kept alive only by a feeding tube. For the right to remove that feeding tube, Ms. Cruzan's family took their case all the way to the U.S. Supreme Court, which ruled that the Cruzans had not provided "clear and convincing evidence" that Nancy Cruzan did not wish to have her life artificially preserved. The family later presented evidence of Ms. Cruzan's wishes to the Missouri courts, which allowed them to remove the feeding tube in 1990.

ACTIVE EUTHANASIA AND ASSISTED SUICIDE

Active euthanasia involves deliberately administering medical treatment that causes the death of the patient. In assisted suicide the patient, upon her own request and after an assessment to determine her competence to make this decision, is provided with a lethal dose of medication. The patient

self-administers this medication, thereby committing suicide. According to a 1997 Gallup Poll, most Americans by that point supported the legalization of assisted suicide.

Some consider assisted suicide to represent active euthanasia, in which deliberate medical treatment is provided, which leads to death. Proponents of assisted suicide disagree, however. They point out that in assisted suicide a lethal dose of medication is self-administered. This makes assisted suicide different from active euthanasia, in which a physician provides the fatal treatment (Reith and Payne 2009).

Patients' requests for assisted suicide are often motivated by physical symptoms and functional losses related to illness, loss of sense of self, and fears about the future (Reith and Payne 2009). There is some evidence, however, that somatic pain is not as strong a factor in a patient's request for assisted suicide as is emotional pain and loneliness (Schroepfer 2008; van Baarsen 2008). Depression, lack of social support, and lack of hope are determining factors; other findings have indicated, though, that depression was not a factor and that the main motivator for a request for assisted suicide was control and autonomy (Reith and Payne 2009). There is evidence and argument, however, that requests for assisted suicide may be withdrawn when patient concerns are identified and addressed (van Baarsen 2008).

In 1997 the U.S. Supreme Court ruled that mentally competent terminally ill people do not have a constitutional right to physician-assisted suicide, leaving the issue up to the states. Assisted suicide of patients within hospice programs was legalized through Oregon's Death with Dignity Act in 1995 and then again in 1997. In response to Oregon's law, Attorney General John Ashcroft issued a directive criminalizing physician-assisted suicide. This ruling was overturned by federal court in 2004, however. Passage of Oregon's law has led to similar efforts in other states, and Montana and Washington legalized physician-assisted suicide in 2008.

In contrast, some states have passed laws criminalizing assisted suicide. In 1996 the U.S. Circuit Court of Appeals overruled such a law in New York State. In addition, Congress passed legislation barring taxpayer dollars from financing physician-assisted suicide. Roff (2001) suggested that the establishment of federal standards, rather than allowing states authority in this matter, may help to resolve the debate. Unsurprisingly, in addition to the legal debates occurring around these issues, ethical dilemmas occur for clients and health care providers. This will be discussed in the next section.

ETHICAL DILEMMAS

Ethical dilemmas occur when there are conflicts between value constellations. Professional codes of ethics, societal conventions, religious beliefs, laws, and family traditions, among others, may conflict with each other. Conflicting values may also be contained within one value constellation.

Several ethical dilemmas arise within passive or active euthanasia. Client self-determination is an important value in both hospice philosophy and the Code of Ethics of the National Association of Social Workers. It is a value also contained within the Patient Bill of Rights and the Patient Self-Determination Act. In a case where a patient refuses life-sustaining treatment or requests assisted suicide, however, the value of client self-determination conflicts with the medical profession's value of professional beneficence and nonmalificence. The Hippocratic Oath commits physicians to do no harm and to make decisions for the benefit of his patients. The physician may invoke "therapeutic privilege" and make decisions without discussion with the patient, if, in the judgment of the doctor, the patient would become worse if informed of the prognosis. In the same situation, the value of quality of life, as well as law about informed consent, conflicts with the religious value of sanctity of life. These are ethical principles that we all agree to, but how do we translate them into practice?

There are two major perspectives regarding how to rank these values and decide what is most important in a given situation. The *deontological principle* relies on duty, law, rules, based on an a priori agreement on essential facts. Proponents have a perspective about what is right to do, about the intrinsic morality of an act. This perspective is not concerned with consequences of the act. From this perspective, a terminally ill person would be resuscitated and placed on life support, because saving life is the right thing to do, regardless of the suffering of the patient or the financial impact on society.

An alternative perspective is the *utilitarian principle*. The focus of this perspective is the consequences of an action. Concern is for society as a whole rather than the individual; proponents aim toward the greatest good for the greatest number of people. From this perspective, it would be considered better not to resuscitate the patient, based on concern for quality of life and cost of a treatment that is considered futile. The money saved by withholding futile treatment can be used instead to provide a basic level of care for all Americans. The treatment may even be withheld for patients who request it—insurance companies may not cover the cost of futile treatment, and some physicians do not believe it is appropriate to provide futile care. A drawback of this approach is a lack of agreement about what is best

for society, necessitating choosing the majority opinion. This approach may thus fail to honor minority opinions.

Some ethicists have tried to find a middle ground between the two poles, arguing that one must consider both the ultimate ends and the intrinsic morality of the action. Ethics committees established in hospitals struggle to resolve these value conflicts. As discussed earlier, these decisions have been the subject of court battles and news headlines as our culture struggles to come to terms with end-of-life care in an age in which life can be sustained in the absence of quality of life. One approach to resolving these questions has been in the effort to establish advance directives.

ADVANCE DIRECTIVES

A situation in which ethical decisions become particularly difficult is when the patient is incapacitated and unable to make his wishes known. In 1990 the federal government addressed this issue through the Patient Self-Determination Act. Under this law, hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations that participated in the Medicare or Medicaid programs were required to develop policies and procedures, keep chart documentation, and inform and educate patients, family members, and staff about the patient's rights under state law to prepare *advance directives*.

Advance directives include *living wills*, *medical powers of attorney*, and *do not resuscitate* orders. A living will is a legal document prepared by the patient which specifies the patient's wishes regarding life-sustaining treatment. A medical power of attorney establishes a legal right for a designated surrogate to make health care decisions for the patient if the patient is physically or mentally unable to do so. A do not resuscitate (DNR) order expresses the patient's wish not to receive cardiopulmonary resuscitation at the point of death. Under the Patient Self-Determination Act, providers must ask patients whether they have executed an advance directive and document the existence or nonexistence of patients' preferences in their medical records.

ADVANCE DIRECTIVES POLICY CONSIDERATIONS

Despite the Patient Self-Determination Act, in practice many people die without self-determination in end-of-life care preferences. This law has

been controversial, and its enforcement is questionable (Arons 2004; Werth and Blevins 2002). In general, fewer than 25 percent of Americans have established advance directives (Arons 2004). This is especially true among younger individuals, men, and individuals representing diverse cultural and economic groups (Galambos 1998).

Providers struggle to resolve how to comply with this law, and compliance may be limited to inquiry about established advance directives and provision of a pamphlet by an admissions clerk. Questions asked at admission have not resulted in many advance directives being established, even when the admissions interview is with a social worker (Happ et al. 2002). Health care providers are compliant with providing information and developing policies, but not in documenting patients' preferences in their charts or in complying with these preferences (Galambos 1998).

BARRIERS TO ESTABLISHING ADVANCE DIRECTIVES

In the absence of an advance directive, physicians may fear liability (Reith and Payne 2009) and feel obligated to provide life-sustaining treatment. States may have requirements for resuscitation outside the hospital unless an advance directive is produced (Keigher 1994). Barriers to establishing advance directives include ineffective methods of promoting advance directives and lack of communication between patients and their physicians and family members (Bomba, Morrissey, and Leven 2011).

INEFFECTIVE METHODS OF PROMOTING ADVANCE DIRECTIVES Questioning by an admissions clerk has not proven to be effective in promoting the use of advance directives. An approach that was extremely successful in a home health agency, in contrast, involved a social work visit in the home to discuss end-of-life issues. In this project eighty-three of ninety-four participants were willing to complete an advance care planning process in their homes, and many enrolled in hospice after this process (Ratner, Norlander, and McSteen 2001). Multiple social work sessions with clients should be held, geared toward the individual's values (Reith and Payne 2009). Galambos (1998) recommends that public education about advance directives needs to begin when individuals are still young and healthy, and Arons (2004) advocates for social workers to become involved in policy practice in this area. Bomba, Morrissey, and Leven (2011) have developed and tested a Community Conversations on Compassionate Care Program

that they found to be successful in encouraging individuals to complete advance directives.

LACK OF PATIENT-PHYSICIAN COMMUNICATION   Physicians fail to inform patients and families about the natural progression of a disease and the quality of life that likely will accompany it (Zilberfein and Hurwitz 2004); thus the patient is unable to give "informed" consent. The inequality of the patient-physician relationship creates an atmosphere in which patient preferences are not sought by the physician (Arons 2004). Physicians place orders to limit therapy in the patient's chart without discussion with the patient (Levin et al. 1999); perhaps this partially reflects a value on physician authority rather than patient self-determination.

LACK OF PATIENT-FAMILY COMMUNICATION   There is also a lack of communication between patients and family members and friends about end-of-life care wishes (Bomba, Morrissey, and Leven 2011). End-of-life care decisions tend to be collaborative (Keigher 1994), made at the time of the illness rather than in advance, and patients tend to leave decisions up to loved ones rather than communicating preferences. Providers have expressed doubt that this surrogate decision making accurately reflects patient wishes (Neuman and Wade 1999). Sutton and Liechty (2004) suggest that support groups may be helpful in allowing patients and loved ones to develop the ability to communicate about these issues.

BARRIERS TO IMPLEMENTING ADVANCE DIRECTIVES

Even when advance directives are completed, they may not be upheld by health care providers or significant others (Reith and Payne 2009). Barriers to implementation of advance directives include lack of communication between patients and providers, value conflicts between patients and providers, and conflicting patient and family preferences.

LACK OF COMMUNICATION BETWEEN PATIENTS AND PROVIDERS   A majority of individuals with advance directives have not made their physicians aware of them (Galambos 1998). Bomba, Morrissey, and Leven (2011) have developed programs to promote physician awareness as well as implementation of advance directives.

VALUE CONFLICTS BETWEEN PATIENTS AND PROVIDERS   This author and colleagues (Reese et al. 2005) found that medical students were less favorable toward palliative care than were citizens in their community. Physicians and social workers have contrasting training and values, which may lead to conflict (Nadicksbernd, Thornberry, and von Gunten 2011). Violation of patient wishes may occur in either direction, however, with life-sustaining treatment being removed without patient or family consent or treatment being continued despite patient and family wishes to the contrary (Galambos 1998).

CONFLICTING PATIENT AND FAMILY PREFERENCES   A study by this author (Reese 2000) found that the most important factor in placement of hospice patients in the hospital by family members, rather than honoring the wish to die at home without life-sustaining treatment, was denial of their terminality. If family members' preferences conflict with patient preferences, physicians may prefer to cooperate with the family member's preferences (Galambos 1998). It is important to communicate to patients and families the consequences of a 911 call or aggressive treatment, particularly when the patient has signed a DNR order (Gerbino and Henderson 2004).

Clearly, these legal and ethical issues are still unresolved. Policy problems and practice problems result. The remainder of the chapter will review the current status of end-of-life care in the U.S. and make recommendations for changes that may help to develop the field.

CURRENT STATUS OF END-OF-LIFE CARE IN THE U.S.

Although active debate is still ongoing about end-of-life care, and opinions differ by geographic region and by ethnic, cultural, or religious group, hospice philosophy has taken hold within the dominant culture of the U.S. The majority of Americans want to die at home and would want palliative rather than curative care in terminal illness (National Hospice and Palliative Care Organization 2002). Intensive care patients from the dominant culture say that they are prepared to shorten healthy life for better care at the end of life (Bryce et al. 2004). An Oregon study found that most individuals who died in 2000–2002 had advance directives and were enrolled in hospice (Tilden et al. 2004).

Nationally, though, despite American orientation toward the major tenets of hospice philosophy, almost 50 percent of Americans still die in the hospital. This varies across the country, with 73 percent dying in the hospital in Washington, DC, and 32 percent in Oregon (Hansen, Tolle, and Martin 2002). An average of only 38.5 percent of Americans died under the care of a hospice in 2008 (National Hospice and Palliative Care Organization 2009).

In addition, patients are referred to hospice shortly before death; the median length of stay was nineteen days in 1998 (General Accounting Office 2000) and is currently reported by the Centers for Medicare and Medicaid Services (2008) as being approximately fourteen days. Entering hospice at this late stage makes pain and symptom management the main objective, leaving little time for psychosocial or spiritual intervention (Kovacs, Bellin, and Fauri 2006).

FACTORS LIMITING USE OF HOSPICE

Factors limiting hospice use include the same ones that limit the use of advance directives: ineffective methods of promoting hospice and lack of communication and value conflicts between patients, physicians, and family members. The Medicare requirement for a prognosis of six months or less acts as a barrier as well. Factors that particularly act to limit access for diverse cultural groups include financial concerns of health care providers and Medicare regulations including referral by a physician, the requirement for a *primary caregiver* (a significant other, living in the home, who agrees to take primary responsibility for the care of the patient), and lack of reimbursement for inpatient and curative care. Finally, one factor that limits use of hospice is a philosophy differing across cultural and religious beliefs. Those with strong religious faith, among many diverse cultural groups, want to extend their lives through terminal illness and oppose physician-assisted suicide.

Medicare coverage of hospice, though a great benefit to the field, initiated a move away from the holistic, volunteer-oriented origins of hospice. Professionalism of hospice and socialization into the health care system culture eventually resulted in an overemphasis on physician and nursing care and a concomitant lack of emphasis on psychosocial and spiritual needs (Parker Oliver et al. 2009). Thus a major reason for inability to consider hospice is

not routinely addressed—the denial of terminality experienced by patients, family members, and physicians themselves.

Medicare requires that a patient be certified as terminally ill by a physician to be eligible for insurance coverage under the Medicare Hospice Benefit. This requirement acts as a major barrier to hospice access for diverse cultural groups, as diverse groups are less likely to have health insurance than the dominant culture (Reese et al. 1999). In addition, preparation for end-of-life care is still not routinely provided in medical training; thus physicians may not even be familiar with the option of hospice. As with advance directives, physicians may have values that are more oriented toward curative care than are their patients' values; this may prevent them from providing the option of palliative care (Reese et al. 2005).

In addition, physicians are uncomfortable giving bad news and tend to be overoptimistic in the prognosis given to patients and significant others (Werth and Blevins 2002). Physicians lack skills in communicating the prognosis and treatment options to patients; thus conversations about terminality between patients and health care personnel are frequently inadequate or even nonexistent (Reith and Payne 2009).

This lack of physician communication skills, paired with an absence of interdisciplinary care, makes it unlikely that clients are presented with the option of hospice by their health care providers. Those who are referred to hospice are likely to be referred very late (Teno et al. 2007), when the fact of terminality is obvious and curative care options have been exercised up until the last weeks before death. A study by this author (Reese 1995) found that a number of home health care patients that were considered terminally ill by their nurses did not have a terminal prognosis according to their physicians. Most of the physicians referred these patients to hospice soon after, however, where they died shortly thereafter.

Despite this, due to a lack of public education by hospices, referral by physicians remains the major way that patients learn about hospice. Misinformation abounds, particularly among diverse cultural groups, including the idea of hospice as lack of care or even as a form of active euthanasia for all patients. Even more frequently, patients have never heard of hospice. This explains the findings that although most Americans are oriented toward hospice philosophy, few die under the care of a hospice (National Hospice and Palliative Care Organization 2002).

The Medicare requirement limiting care to persons with a prognosis of six months or less also creates a barrier to hospice access. Physicians have

difficulty making this determination (Center for Bioethics, University of Minnesota 2005), which may be appropriate for cancer but not for other diagnoses which are not as predictable or are characterized by a lengthy dying process. In 1998 the percentage of hospice noncancer admissions decreased dramatically, reflecting the problems associated with determining a six-month prognosis for these patients.

A history of investigation by the Health Care Financing Administration (HCFA, now Centers for Medicare and Medicaid Services) has exacerbated this problem. In 1994 HCFA published a memo about problems with questionable physician certification of hospice patients. They conducted an investigation of doctors who had referred patients to hospice who did not die within six months. Afterward physicians were fearful of being punished if an enrollee lived longer than six months and for this reason hesitated to refer terminally ill patients to hospice (Werth and Blevins 2002). Medicare has since developed a policy that allows recertification of hospice patients who live longer than six months; it is important to educate providers about this policy.

Financial concerns of health care providers also act as barriers to hospice referral. In the early days of hospice, when services were provided on a volunteer basis, services were offered free of charge to those who could not pay. This tradition has continued until today in many hospices. In some, however, lack of insurance acts as a barrier, particularly for those from diverse cultural groups. In addition, some authors assert that a patient choice of solely palliative care may go against a provider emphasis on full use of technology regardless of associated cost (Finn 2002).

Several other Medicare policies act as barriers to hospice access for diverse cultural groups. Medicare requires that a primary caregiver be available in the home. Research has indicated, though, that, for many culturally diverse individuals, family members must work and are not able to stay at home with the patient (Werth and Blevins 2002). Also, the Medicare requirement for an informed consent that acknowledges terminality and foregoes life-sustaining treatment, as well as lack of Medicare Hospice Benefit coverage for hospice stays or curative care, act as barriers for cultural groups that believe that accepting death is a lack of faith (Reese et al. 1999).

Those with a strong religious faith, including many from diverse cultural groups, want to extend their life in terminal illness (Reese et al. 1999). The rise of the Republican right, with its emphasis on conserva-

tive Christian principles, has recently promoted an orientation toward life-sustaining treatment in terminal illness. An absolutist perspective that assumes adherence to these principals should be enforced through law regardless of individual differences in philosophy and values has lent even more force to this trend.

An example is the 2005 case of Terri Schiavo, a brain-damaged woman who was being served by a hospice in Florida. Her husband had consented to palliative care for her, claiming that she had communicated to him her wish not to be kept alive artificially if in a persistent vegetative state. Ms. Schiavo had received artificial nutrition for fifteen years after her heart had stopped in 1990. Her feeding tube had been removed by court order in March of 2005, but her parents fought a lengthy court battle to have the tube reinserted. Politicians intervened in the case, passing emergency legislation to order doctors to reinsert the tube or calling for federal courts to review the case—including the state governor, U.S. House and Senate, and even President Bush, who signed a bill into law in the middle of the night. A series of court rulings, progressing up to the U.S. Supreme Court level, upheld Ms. Schiavo's right to die, however. Public sentiment reflected and may have influenced the actions of the politicians (Branford 2005). Citizens conducted demonstrations, and a California businessman offered Terri Schiavo's husband one million dollars to keep his wife alive (he refused).

RISE OF PALLIATIVE CARE AS A SEPARATE FIELD OF PRACTICE

Hospice is a form of palliative care, in which the goal is palliation of symptoms rather than cure of an incurable disease. Hospice provides treatment specifically for terminally ill patients. Palliative care is also provided outside the hospice setting to patients who are chronically ill. For example, HIV cannot be cured, but current treatments relieve symptoms and delay the course of the disease for a number of years. Thus patients with this illness, who are not considered to be terminally ill in the sense that they are expected to die within six months, may be seen on an outpatient basis in a nonhospice program referred to as "palliative care."

Terminally ill patients who have not chosen hospice may also receive care for their symptoms from a palliative care program, however. Partially

due to a lack of hospice outreach, and partially in response to the barriers to hospice referrals already described, palliative care for terminally ill patients has risen in the past couple decades to be a separate service from hospice care.

Palliative care as it is provided in the United States addresses many of the barriers to hospice referral. Medicare regulations relevant to hospice do not pertain to palliative care. Denial of terminality does not have to be addressed, since patients do not have to sign an informed consent recognizing terminality, and physicians do not have to have a conversation about the prognosis. Patients can receive curative care as well as palliative care, thus value conflicts with providers and family members are less likely. The Medicare requirement for a six-month prognosis does not apply, physicians do not have to certify that the patient is terminally ill, and there is no requirement for a primary caregiver. Lack of service to those without health insurance is still a concern and presents a barrier to access for diverse cultural groups.

The field of palliative care has been developed in competition with hospice and has not used the lessons hospice has learned. Palliative care programs don't always provide interdisciplinary care; thus they may not adequately address psychosocial and spiritual issues with clients.

RECOMMENDATIONS FOR ADDRESSING THE BARRIERS TO HOSPICE ACCESS

Recommendations for addressing the barriers to hospice access include an interdisciplinary approach to care within physicians' offices in which social workers provide the counseling to patients and families. Hospice care and philosophy should be integrated into other services; the hospice team should provide consultation to staff and intervention with clients from the first diagnosis until death. Care should be a continuum—moving from diagnosis to palliative/curative care, then to hospice. Medicare coverage of these consultation services should be provided, and the hospice social worker should play a major role in consultation.

In addition, general education of consumers must be provided by the hospice field, and Medicare reimbursement is needed for preadmission informational visits by hospice staff. Public education efforts should be cognizant of the relevance of their message to diverse cultural groups. Those without access to health care may not be able to relate to public education

about the right to die and refuse treatment (Keigher 1994). In addition, particular emphasis should be placed on dispelling myths among diverse cultural groups about services provided (Werth and Blevins 2002).

Medicare eligibility requirements should also be made more flexible, redefining end-of-life by severity of illness as opposed to prognosis (Werth and Blevins 2002). Access would also be increased, particularly for diverse cultural groups, by allowing patients to continue to receive disease-modifying treatment along with hospice care.

RECOMMENDATIONS FOR THE PALLIATIVE CARE FIELD

According to the hospice philosophy, patient awareness of terminality is necessary for a good quality of life in death and dying. This awareness is necessary for informed choices within self-determination, including making decisions about end-of-life care consistent with one's cultural and religious beliefs and communicating preferences about one's environment. Awareness is also necessary to address psychosocial issues such as suicidal ideation, death anxiety, social support, financial arrangements, safety and comfort issues, anticipatory grief, and denial itself. Awareness must also be present to address major spiritual issues including meaning of life and suffering, unfinished business, clarification of religious beliefs, relationship with the Ultimate, isolation, and transpersonal experiences.

Denial of terminality can be a positive coping skill. In most cases patients move in and out of awareness of terminality according to their emotional resources at the time. When they are in an emotional state in which they can handle this awareness, they need someone to talk with in order to address psychosocial and spiritual issues. Thus we recommend that palliative care programs develop a collaborative relationship with hospice teams to take advantage of their skills in addressing these issues. In particular, social workers and spiritual caregivers should be called upon to provide services to clients in these areas. The time to begin this collaborative approach is at the time of diagnosis, long before the patient has to address terminality.

The ability of patients within palliative care programs to move back and forth between curative and palliative care is beneficial; this can create access for those whose religious beliefs prevent them from resigning themselves to terminality. Lack of service to those without health insurance needs to be addressed, however, perhaps by setting up a foundation for such care.

ADDITIONAL HOSPICE POLICY ISSUES

Many problems abound with inadequate Medicare reimbursement of hospices. This is a major factor for hospice financial well-being, since most hospice patients are covered by Medicare. The Medicare Hospice Benefit provides a per diem rate to hospices, and if the expense of the treatment is more than the reimbursement, the hospice must absorb the loss (Werth and Blevins 2002). The first and last weeks of hospice enrollment tend to involve the most expensive treatment, so the short hospice stay so often seen today intensifies these financial difficulties. These financial issues may make it difficult for hospices to provide the most effective (and most expensive) pain medications. Recommendations include increasing per diem rates, adjusting reimbursement for patients with expensive treatments, making a minimum payment of fourteen days, allowing reimbursement to nurse practitioners and physicians' assistants, placing a ceiling on potential expenditures, and allowing social workers to bill separately for services (Goldberg and Scharlin 2011).

Rural hospices may have particular difficulty making ends meet. The Medicare reimbursement rate for rural hospices is lower, even though they may incur additional expenses associated with travel. A proposal has been made to Congress for demonstration projects to allow individuals in rural areas to receive inpatient hospice care and respite care longer than is allowed in the hospice legislation. Recommendations have also been made for a 10 percent increase in rural reimbursement rates and adjusting for travel expenses for rural hospices (Werth and Blevins 2002).

Another policy issue concerns the services provided by for-profit hospices. The number of for-profit hospices quadrupled from 1994–2004, and research has indicated that patients of for-profit hospices received a significantly narrower range of services than patients of nonprofit hospices (Carlson, Gallo, and Bradley 2004).

Another question concerns encouragement of hospice enrollment by Health Maintenance Organizations (HMOs). Some authors suggest that HMOs may be encouraging enrollment in hospice because of the cost savings. This raises a question about patient self-determination in end-of-life care treatment choice.

Finally, the domination of the hospice field by physicians and nurses is also a concern due to the current overemphasis on a biomedical model of care. The holistic model first developed by Dame Cicely Saunders has been

neglected, with nonmedical staff referred to as "ancillary staff." Chapter 2 will discuss the current status of social work in the hospice field.

CONTINUUM OF CARE

The National Hospice and Palliative Care Organization advocates for "continuum of care" in order to address barriers to hospice referral, utilization, and financing. At present, the Centers for Medicare and Medicaid Services (CMS) restricts Medicare reimbursement for hospice services to patients who have been certified by a physician as having six months or less to live. If so certified, CMS will pay for palliative care, but not curative care. In order to receive hospice services, the patient must sign an informed consent statement recognizing the terminal prognosis. These regulations present barriers for patients with chronic illnesses in which a terminal prognosis cannot easily be made (such as congestive heart failure) as well as for patients and families who are not willing or psychologically or spiritually ready to give up all curative measures.

Palliative care programs in the U.S. are free of these restrictions, but often do not utilize the knowledge developed within the hospice field. For example, they may not provide holistic care through an interdisciplinary team that includes a social worker and a spiritual caregiver (although this is becoming more common). Thus, they may not fully address psychosocial and spiritual issues pertaining to terminal illness.

The idea of continuity of care includes two approaches: 1. supplementing existing hospice services with palliative care integrated into nonhospice care settings to form a continuum of care, of which hospice is a part, and 2. expanding the scope and mission of hospices to serve populations of patients who have longer to live and who are in various health care settings (Jennings et al. 2003). These approaches can help meet the psychosocial and spiritual needs of patients and families who need intervention to help them prepare for end-of-life care decisions consistent with acceptance of a terminal prognosis. Clients need this intervention through an interdisciplinary team, beginning at first diagnosis of a life-threatening illness and continuing through curative, palliative, and end-of-life care (Schumacher 2003).

This chapter discussed the history of our approach to death and dying in the United States of America. From a tradition of dying at home surrounded by

loved ones, we transitioned to a majority of deaths occurring in the hospital. Often these deaths occur during the administration of life-sustaining treatments. The hospice philosophy, developed first in England and promoted in the U.S. by Elisabeth Kubler-Ross, encouraged palliative rather than curative care in terminal illness, with patient quality of life and self-determination among its highest values. Hospice care in the U.S. has usually been provided in the home, although inpatient hospices have been developed as well.

Health care costs have been a major social problem in our country for decades, and since hospice care was found to be less expensive than life-sustaining treatment, Medicare and Medicaid developed coverage of all hospice expenses including medication and equipment, making it an extremely beneficial service for dying patients and their families. Health insurance coverage of this approach to end-of-life care led to standards of practice, including the requirement for social work services and evaluation techniques, and has greatly helped to expand and develop the hospice field.

Health insurance coverage has also led to some policy problems, though, which include the requirement for a physician to make a terminal prognosis—in other words, that the patient will die within six months. In addition, the patient must sign a statement recognizing the terminal illness and foregoing curative care. Making an accurate prognosis is extremely difficult, even impossible, for a physician to do, and being ready to sign an informed consent for only palliative care is very difficult for a patient to be ready for without preparation through social work intervention. This is especially difficult for some ethnic and racial communities with a history of mistreatment by the health care system and/or who rely on the family and their elders to make such decisions rather than the patient. These problems have served as barriers to hospice utilization and in part have led to the development of the field of palliative care, which, in addition to treating chronically ill patients who are not necessarily terminally ill, may treat terminally ill patients who are not ready or aware enough of their prognosis to go through the process required for hospice admission.

Alternatively, in contrast to the barriers preventing patients from taking advantage of hospice care in terminal illness, there has been a movement toward physician-assisted suicide. The main motivation for this appears to be patients' desire for control of their illness and dying process, although there is a need for differential diagnosis to make sure depression and untreated symptoms are not the problem. In this chapter we discussed ethical issues having to do with end-of-life care including physician-assisted suicide.

We also discussed advance directives as a tool for upholding patient self-determination to help them communicate their wishes in end-of-life decisions. We concluded this chapter with a discussion of policy issues in the field and some recommendations for policy change, including developing a continuum of care between life-sustaining and palliative care options. Chapter 2 will focus in specifically on the field of social work within hospice care; we will review the history, efforts toward development, and current status of the profession of social work on the hospice interdisciplinary team.

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