

End-of-Life Care

BACKGROUND

Advances in health care technology have given physicians the ability to prolong life in ways that would have seemed impossible only a few years ago. Often, however, the psychosocial consequences of prolongation of life are not considered as an important part of end-of-life decision making and care. Advances in critical care medicine enhance physicians' and clients' opportunities to avoid discussions about death, quality of life, and suffering.

Decisions regarding end-of-life care should be considered at numerous junctures over the course of one's life, not just when diagnosed with a terminal illness or faced with an acute, life-ending event. End-of-life decisions encompass a broad range of medical, spiritual, and psychosocial determinations that each individual should make before the end of her or his life. A person may choose to delegate end-of-life decisions, with or without an advance directive, depending on an individual's capacity to do so. Ideally, individuals decide to address such decisions through advance care planning. In emergencies, when care consideration is not possible, difficult decisions may need to be made by family members and friends, who are often ill-prepared to decide what their loved ones might have wanted. Such decisions can include where a person plans to spend the final months before death and the degree of self-sufficiency and technological intervention she or he wishes during that time. The use of personal, family, and social resources to carry out these decisions may change, depending on the course of the particular illness, and are among some of the most important decisions individuals and their loved ones face (NASW, 2004).

Definitions

For the purpose of this position statement, the following are common terms and definitions associated with end-of-life care. It should be noted that many of these terms are interpreted differently, based on state laws and regulations, across the United States. Here, for the sake of clarity, we describe our specific use of the terms.

Advance Care Planning. Advance care planning encompasses all aspects of an individual's desires for end-of-life care, including living will, health care proxy, "do not resuscitate" orders, and funeral planning.

Health Care Directives. These are written statements that instruct family, friends, medical professionals, and others how an individual wishes to be treated at the end of life, including medical care preferences (resuscitation orders, surgeries, artificial feeding, and organ donation, for example) and how his or her affairs are to be settled. Advance directives include the Durable Power Of Attorney for Health Care and Living Will (also known as Directive to Physician) documents (see definitions below). The appointment only takes effect when individuals are no longer able to make decisions for themselves. It is a Medicare requirement that each client, on admission to a hospital, nursing home, or end-stage renal disease (ESRD) treatment facility be asked if she or he wishes to assign a health care power of attorney, or if she or he has an advance care directive or health care proxy (Patient Self Determination Act, P.L. 101-508).

Minors. Most states will not recognize a formal advance directive signed by a minor, even if he or she is living independently. In most situations, parents and legal guardians retain legal authority to make decisions about medical treatments for a child (Institute of Medicine, 2003).

Decisional Capacity. Decisional capacity is the ability of an individual to understand his or her medical condition, to participate in treatment planning in and out of hospital care, to understand the consequences of his or her decisions, and to meet all other criteria as defined by law (Last Acts, 2001). Decisional capacity can be determined by a psychiatrist or any other physician. The legal definition may vary based on state laws and regulations.

Do Not Resuscitate (DNR) or Do Not Attempt Resuscitation (DNAR). A DNR is an order written by a physician indicating that cardiopulmonary resuscitation is not to be performed. This may also include removal of medications that artificially maintain a blood pressure and the discontinuation of artificial nutrition (New York State and Missouri are exceptions on nutrition). A DNR or DNAR option is discussed with a client or health care agent or family member, but the recommendation not to resuscitate is a medical decision, thereby alleviating a client or family member from making this decision.

Double Effect. This term is related to the ethical principle of “the rule of double effect,” which refers to medical treatment that can both produce a desired effect, such as pain relief, but also cause secondary adverse effects, including death. The logic, in effect, is that if the treatment is given only for the desired effect, to relieve pain, the treatment is ethical, even if one could reasonably expect the client to die from the treatment (Last Acts, 2001). Many experts cite morphine given in hospice care as an example. It has powerful pain-relieving properties, but also depresses respiration, which can lead to death.

Durable Power of Attorney for Medical Decision Making (Health Care Proxy). A durable power of attorney for health care decisions is a way to give another individual legal power to make medical decisions when the individual no longer can. The written form used to designate the proxy is also called a durable power of attorney for decision making in health care matters (Lynn & Harrold, 1999). Different states have different versions of this form.

Euthanasia. Euthanasia is the intentional act of ending the life of an individual who would otherwise suffer terribly from a terminal condition. This act is illegal in the United States and also referred to as “mercy killing” (Lynn & Harrold, 1999). It is not to be confused with physician-assisted suicide, described later in this statement.

Family. Anyone the client defines as her or his family, including spouses, partners, parents, siblings, and friends falls into this category. Friends and partners may not have legal status to make decisions for clients unless they are designated as such by a durable power of attorney for health care decisions, but their input should be sought and noted.

Medical Futility. Treatments and procedures provided near the end of life that offer little or no benefit are called medically futile (Bartlow, 2000). The underlying idea of futile care is that if an individual or family member wants life-sustaining treatment, but the physician does not believe the quality of the individual’s life justifies the physical burdens of care on the patient, the doctor has the right to withhold any such treatments other than comfort care (Smith, 2002).

Hospice Care. Hospice care is care provided under eligibility guidelines, including diagnosis and prognosis, that focuses on caring, not curing, and in most cases, is provided in the client’s home. The focus is on ameliorating physical, psychosocial, and existential suffering (National Hospice and Palliative Care Organization, 2003).

Incompetent. This is a legal term that can only be applied and decided by a judge. This term is often confused with diminished or lack of decisional capacity.

Life-Sustaining Treatment. Life-sustaining treatments are expected to extend life. In the context of end-of-life care, these may also be considered to be futile or death avoidant.

Living Will (Directive to Physician). A living will is a legal document that declares an individual's wish to die a natural death. The document informs the physician that, in the event of a terminal or irreversible condition, she or he does not wish to have her or his life prolonged by artificial or extraordinary means. These documents are not legally binding in all states.

Pain. Pain is the physical sensation resulting from physical illness or conditions that cause discomfort for a client. There are varieties of verbal and nonverbal methods to assess pain. Severity of pain is whatever the client tells the health care provider. Pain should be assessed for clients with and without consciousness (Joint Commission on Accreditation of Healthcare Organizations [JCAHO], 1999).

Palliative Care. Palliative care is an approach that improves quality of life for clients and families facing life-threatening illness (NASW, 2004). This approach is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2003).

Palliative Sedation. This treatment involves the monitored use of drugs and other procedures intended to induce varying degrees of relief of unmanageable, intractable, and intolerable symptoms in imminently dying clients (Hospice and Palliative Nurses Association, 2003).

Physician-Assisted Suicide. In physician-assisted suicide, a client ends her or his life with the prescription requested of and provided by a physician for that purpose. As of 2005, the state of Oregon was the only state where this act is legally permissible. In all cases, the client must have decisional capacity and meet other criteria as defined by law (Oregon Department of Human Services, 1997).

Suffering. Although suffering can be both physical and psychological in nature, it can extend itself in the dying trajectory to the existentialist level. Depression or existential suffering refers to the feelings of misery, fear, and immobilization, as well as the search for meaning an individual may feel at the end of life. As soon as an individual begins the difficult work of grieving, including "struggling with," and through depression, the road to resolution, acceptance, and healing has started (Bartlow, 2000; Peck, 1997).

Terminal and Irreversible Condition. This phrase defines a condition with no reasonable chance of recovery or a condition caused by injury, disease, or illness, which, within reasonable medical judgment, would produce death within a short time, and for which the application of life-sustaining procedures would serve only to postpone the moment of death or be futile.

Withdrawal or Withholding of Treatment. These are acts that eliminate interventions that prolong death or that create further pain and suffering. Action is followed at the direction of the client or his or her health care agent. Withdrawal of treatment may include the following: removal of medicines that artificially maintain blood pressure, and extubation and withdrawal of ventilatory support. Withdrawal comes with assurances that the physician will provide enough sedating medication to avoid patient and family suffering.

Legislation

In recent years, a proliferation of state legislation has been introduced concerning assisted

suicide, most notably Oregon's 1997 implementation of physician-assisted suicide. However, state legislatures across the country are debating similar "death with dignity" bills, many of which would authorize physician-assisted suicide. Legislatures and state ballot initiatives that recently have discussed death with dignity bills include those in Arizona, Florida, Hawaii, Maine, Wisconsin, Wyoming, and Vermont. In 2001 U.S. Attorney General John Ashcroft filed suit against Oregon to overturn the Death with Dignity Act and stop its proliferation to other states. In 2004 a federal appeals court ruled against the Attorney General and upheld the Oregon statute.

Political and social leaders are also attempting to influence personal choice and clinical practice in this area. State legislatures have become involved in such high profile cases as the Terri Schiavo case in Florida and the illegal Jack Kevorkian practice, in which he euthanized several patients. In 2004, the Vatican released an opinion that feeding tubes are medical therapy and cannot be withheld from a permanently unconscious person (Smith, 2004). It is not clear what impact the Pope's statement will have on the nation's Catholic hospitals or health care providers and clients.

The 1990 Patient Self-Determination Act mandated the requirement that hospitals, skilled nursing facilities, ESRD facilities, home health agencies, hospice programs, and HMOs maintain written policies and procedures guaranteeing that every adult receiving medical care is given written information concerning living wills, durable powers of attorney for health care, or advance directives.

A groundswell of new policies and practices in end-of-life care has been positive in recent years. The positive changes include state policies on pain and symptom management, the JCAHO's requirements for pain assessments, reconsideration of state-mandated advance directives, the use of out-of-hospital DNRs, and the increased practice of palliative care.

ISSUE STATEMENT

Social work practice settings addressing end-of-life care include health and mental health

agencies, schools, courts, child welfare and family service agencies, correctional systems, agencies serving immigrants and refugees, military service agencies, substance abuse programs, and employee assistance programs. Social work is a broadly based profession that can meet the needs of individuals and families affected by end-of-life situations. Social workers require guidelines that are compatible with professional and personal ethics, legal parameters, and respect for client self-determination. Furthermore, other professionals may look to social work for guidelines on these complex issues.

Using the expertise in working with populations from varying cultures, ages, socioeconomic statuses, and traditional and nontraditional families, social workers help clients and families across the life span cope with loss, trauma, suicide, dying, death, and bereavement; they must be prepared to assess such needs and to intervene appropriately.

In acknowledging and affirming social work's commitment to respecting diverse value systems in a pluralistic society, we recognize that end-of-life issues as complex because they reflect the varied value systems of different groups. Consequently, NASW does not take a position regarding the myriad moral and value-laden questions associated with end-of-life decisions, but affirms the right of individuals to direct their end-of-life care.

We also recognized that de facto rationing of health care based on age, sexual orientation, religion, socioeconomic status, race, ability to pay, provider biases, and government policy differentially affect people's rights to choose among viable service alternatives and diminishes their ability to give truly informed consent. Social workers should advocate to minimize the effect of these factors when determining the care options available to individuals.

In examining the social work role with clients concerning end-of-life decisions, the following issues must be addressed:

- potential conflict of social work values with those of the clients, clients' families, other health care professionals, or agency settings
- limits of confidentiality, social work licensing laws, and state and federal laws and regulations

- emerging pressures for cost control and rationing of health care (for example, using health care institutions and insurers to encourage use of end-of-life practices to control costs)
- the possibility that individuals would feel the need to hasten their deaths and the social work role of exploring such feelings and discussion with clients
- the necessity to define, defend, and advocate for safeguards that protect individuals and society in the implementation of end-of-life practices
- lack of access to end-of-life care options for all persons.

POLICY STATEMENT

NASW's position concerning end-of-life decisions is based on the principle of client self-determination. Choice should be intrinsic to all aspects of life and death. Social workers have an important role in helping individuals identify the end-of-life options available to them. This role must be performed with full knowledge of and compliance with the law and in accordance with the *NASW Code of Ethics* (NASW, 2000) and *NASW Standards for Social Work Practice in Palliative & End of Life Care* (NASW, 2004).

Often, social workers meet with clients who express a desire to talk about their thoughts and feelings about dying and death. Social workers play an important role in assessing desire-to-die statements; in providing appropriate knowledge, compassion, and skill; and intervening to ameliorate pain and suffering. Social workers can explore and assess all these issues with clients and can educate and direct them to appropriate resources such as pain management, palliative care, or hospice care.

The position of the National Association of Social Workers on end-of-life care provides several areas of consideration and specific action steps for social workers and other providers dealing with this issue.

Practice

- Facilitate client and family understanding of all aspects and options in end-of-life care.
- Provide emotional, psychological, social, and spiritual care and services along the end-of-life continuum.
- Be aware of cultural diversity in end-of-life care practices and beliefs so that culturally sensitive practices in end-of-life care can be used with clients and families.
- Provide access to information to facilitate informed consent for decision making.
- Be aware of client diagnoses and trajectories of illness to best prepare for future health care needs and decisions.
- Discuss and encourage advance care planning if appropriate.
- Be present (if the social worker is comfortable with being present) with the client and family at the very end of life (whatever the site) as appropriate, and when requested by the client or family.
- Be present (if social worker is comfortable with presence) with a client or family in assisted-suicide situations in states where this practice is legal and requested by the client.
- Strive to facilitate continuity of care across all care settings.
- Assess mental health functioning to include assisting in decisional capacity determinations, depression, anxiety, suicidal ideation, and facilitate or provide interventions or referrals for care.
- Be knowledgeable about institutional policies on capacity, advance directives, pain management, futile care, and DNR orders.
- Be knowledgeable about state specific policies on end-of-life care.
- Recognize the importance of an initial and ongoing assessment to provide the appropriate intervention(s) along the continuum of care.
- Be competent in assessing pain and other symptoms.

- Be able to differentiate between pain and existential suffering.
- Act as a liaison with other health care professionals to communicate clients' and families' concerns to the health care team to improve the quality of end-of-life care.
- Provide mentoring and consultation to other health care professionals and social work colleagues and students in the field of end-of-life care.
- Be self-aware of personal values and feelings about dying and death and obtain assistance for the best interests of client, as well as to meet one's own personal needs to resolve issues.
- Refer the client or family to another social worker if your own value system conflicts with your client's decisions.
- Prevent abandonment by care providers of the client or family facing an end-of-life situation.
- Obtain competent supervision when working in end-of-life care.
- Be knowledgeable about hospice care for cancer and non-cancer diagnoses, such as congestive heart failure, diabetes, and ESRD.
- Keep abreast of changes in end-of-life care by participating in continuing education and research activities.

Advocacy

- Advocate for adequate pain control and symptom management in institutional and agency committees and in state and national legislative and regulatory forums.
- Promote access to care for all people facing end-of-life situations.
- Participate in local, state, and national committees, activities, and task forces concerning client self-determination and end-of-life decisions.
- Include education and research on these complex topics in social work curricula.

- Support initiatives, both public and private, that seek to expand the hospice benefit.

REFERENCES

- Bartlow, B. (2000). *Medical care of the soul*. Boulder, CO: Johnson Printing.
- Hospice and Palliative Nurses Association. (2003). *Palliative sedation*. Retrieved May 11, 2004, from http://www.hpna.org/position_PalliativeSedation.asp
- Institute of Medicine. (2003). *When children die: Improving palliative and end of life care for children and their families* (Summary). Washington, DC: Author.
- Joint Commission on Accreditation of Hospitals. (1999). *Pain: Current understanding of assessment, management and treatment*. Retrieved May 11, 2004, from http://www.jcaho.org/news+room/health+care+issues/pain+mono_npc.pdf
- Last Acts. (2001). *What does it mean? Common terms used in talking about end of life care*. Retrieved May 11, 2004, from <http://www.lastacts.org/files/misc/glossary.pdf>
- Lynn, J., & Harrold, J. (1999). *Handbook for mortals: Guidance for people facing serious illness*. New York: Oxford University Press.
- National Association of Social Workers. (2000). *Code of ethics of the National Association of Social Workers*. Washington, DC: Author.
- National Association of Social Workers. (2003). *Client self-determination in end-of-life decisions. Social work speaks: National Association of Social Workers policy statements, 2003–2006* (6th ed., pp. 46–49). Washington, DC: NASW Press.
- National Association of Social Workers. (2004). *NASW standards for social work practice in palliative & end of life care*. Washington, DC: Author.
- National Hospice and Palliative Care Organization. (2003). *What is hospice care*. Retrieved May 11, 2004, from <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3281>
- Oregon Department of Human Services. (1997). *Oregon's death with dignity act*. Retrieved May 11, 2004, from <http://www.dhs.state.or.us/publichealth/chs/pas/pas.cfm>

- Patient Self-Determination Act (PSDA), Pub. L. 101-508, 104 Stat. 1388 (1990).
- Peck, F. S. (1997). *Denial of the soul: Spiritual and medical perspectives on euthanasia*. New York: Harmony Books.
- Smith, V. A. (2004) Pope's feeding-tube declaration pits religion, medicine. *Philadelphia Inquirer*. Retrieved November 17, 2004, from <http://www.philly.com/mld/philly/>
- Smith, W. J. (2002). *Doctors deny some patients hospital care*. Detroit News. Retrieved June 1, 2004, from <http://www.detnews.com/2002/editorial/0201/13/a13-389247.htm>
- World Health Organization. (2003). *Palliative care*. Retrieved May 11, 2004, from <http://www.who.int/cancer/palliative/definition/en/>

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