

## End-of-Life Care and Decision Making

### What We Know

- › Although death is a normal part of the life cycle, clients and clinicians often view death as what happens when medicine fails. This negative view has resulted in a major deficiency in the quality of care provided at the end of life (EOL). In recent years there has been a call for substantive change in EOL care in the United States, along with many initiatives with the goal of providing a more humane and comprehensive approach to care of the dying. Less than 10% of deaths are sudden and unexpected; most people who die experience a gradual deterioration until the active dying phase before death. Yet most people avoid planning for the end of their lives<sup>(20,27)</sup>
  - Client and family awareness of treatment goals and prognosis is a key factor in acceptance of and planning for death<sup>(27)</sup>
  - Specific issues related to the EOL include who should make decisions if the client is unable to, what medical treatment and care are acceptable to the client, the client's wishes regarding resuscitation and hospitalization, how medical care will be paid for, and what the client wishes to happen when he or she dies (e.g. funeral, burial, cremation)<sup>(9,12)</sup>
  - EOL decisions should respect the person's values and wishes while maintaining his or her comfort and dignity. This can be achieved by improving care at the EOL, thus facilitating a "good death"
    - The Institute of Medicine (1997) defines a good death as "one that is free from avoidable suffering for patients, families, and care givers in general accordance with patients' and families' wishes"<sup>(11)</sup>
- › EOL decisions and care vary greatly in different parts of the world because of different attitudes, values, practices, and religious, ethical, and cultural beliefs<sup>(32)</sup>
- › Palliative care (PC), or comfort care, is a specialized type of client care that aims to promote comfort and dignity while maintaining the highest possible quality of life for clients for as long as possible<sup>(30)</sup>
  - By definition, PC can span an extended period of time, encompassing the active treatment phase of disease, disease remissions, recurrences of disease, and the decline in health before death. Although not limited to EOL care, PC usually is provided for clients with terminal illness<sup>(30)</sup>
  - PC is most commonly associated with advanced cancer, although PC is of great benefit for those with nonmalignant conditions as well<sup>(1,17)</sup>
  - Hospice is PC that is provided, often in the home, to clients who are approaching the EOL. Medicare beneficiaries qualify for hospice if they have a life expectancy of 6 months or less; the client must agree to PC rather than curative treatment<sup>(13)</sup>
    - This holistic approach to care involves an interdisciplinary PC team that consists of physicians, nurses, clergy, social workers, other healthcare personnel, the client, and the client's caregivers<sup>(16,28)</sup>
  - Caregivers are the persons who are responsible for the client's day-to-day care. PC often is provided in the home setting by untrained caregivers, including spouses/partners, adult children, relatives, and close friends<sup>(14)</sup>

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- Essential areas of PC, as recognized by caregivers, include adequately managing the client's pain and relieving symptoms, preserving the client's dignity, enabling the client to maintain a sense of control, and helping the client prepare psychologically for death, when appropriate<sup>(26)</sup>
- › Social workers can assess the client's and family members' stances toward dying. Dying may be allowed, resisted through the pursuit of curative care, or contested with disagreement about whether the client is dying; in addition, in mixed-message dying, involved parties disagree as to whether the client is dying<sup>(2)</sup>
- › Advance care planning (ACP) throughout the EOL is an increasingly important aspect of working with clients and their families. ACP, the cornerstone of palliative care, is a process of planning for future medical care in the event the client is unable to make his or her own decisions. ACP should be completed before the client has significant cognitive impairment. It is a continual process, not merely a set of documents or an isolated event. ACP helps reduce uncertainty and minimize confusion and conflict over the client's wishes. There are two primary goals of ACP:<sup>(3,5,8,12,20)</sup>
  - Facilitating communication regarding the client's healthcare goals and desires<sup>(29)</sup>
- › As a result of the error of omission, hospitals still frequently inadequately discuss or document discussion of clients' EOL wishes<sup>(29)</sup>
- › Social workers need to work with clients and families to determine whether the overall goal of care is comfort, survival, or some combination<sup>(2)</sup>
- › Social workers need to be aware of current legislation in their state of practice related to the sharing of healthcare information. California has proposed legislation whereby information about an ill parent could still be provided to adult children even if there is estrangement<sup>(22)</sup>
- Establishing contingency plans to achieve those goals
  - Advance directives and durable power of attorney are legal documents that often are created during the ACP process. The U.S. Patient Self-Determination Act of 1990 requires that healthcare providers advise individuals who are being admitted to a healthcare institution or program of their right to accept or reject medical treatment and their right to make advance directives or leave written instructions about their choices of treatment in case they should become incapacitated. Additionally, clients are provided with information on the value of these documents and instructions for completing the state-specific forms<sup>(3,5,7,20,21,24,28)</sup>
  - Advance directives (AD) provide specific instructions on care and treatment and provide instructions to help guide the client's appointed representative (proxy) in making healthcare decisions. There are various types of directives:<sup>(20,28)</sup>
    - A living will enables the client to put in writing his or her wishes concerning medical treatments. This instructional directive details the amount of care a person wants should he or she become incapacitated (e.g., resuscitation, artificial feeding, mechanical ventilators, defibrillation, antibiotics, dialysis, other invasive procedures)<sup>(8)</sup>
    - Durable power of attorney for healthcare is a legal document that enables the client to designate a proxy should he or she become unable to communicate his or her treatment needs and desires<sup>(28)</sup>
      - Clients need to understand that simply naming a surrogate does not ensure that their wishes will be followed. Surrogates need to be aware that they have been authorized, know the specifics of the client's wishes, and be willing to follow those wishes<sup>(6)</sup>
  - A Physician Order for Life-Sustaining Treatment (POLST) is a medical order written by the physician that establishes a preferred level of aggressiveness in treatment or medical care. It can include a do-not-resuscitate order (DNR) but does not always; likewise, a DNR can be put in place without a POLST. The POLST will typically address the initiation, continuation, withdrawal, or withholding of specific medical interventions (e.g., artificial nutrition, artificial hydration, cardiopulmonary resuscitation, mechanical ventilation)<sup>(19,33)</sup>
    - The POLST can transition between different medical venues (e.g., nursing home to hospital)<sup>(33)</sup>
    - Clients who have a POLST in place have a higher likelihood that their values and wishes will be honored because ambiguities are eliminated<sup>(19)</sup>
    - In the absence of official directives, physicians have a tendency to allow personal social values to influence their EOL decision making<sup>(6)</sup>
  - Legislation regarding advance directives varies among countries. Many have legislation that recognizes advance directives (e.g., United States, United Kingdom, Germany, Spain, Belgium, Netherlands) and accepts them as binding where care is concerned. In the United States, hospitals and providers must maintain policies and procedures with respect to advance directives in order to receive Medicare or Medicaid payment from the federal government.

Other countries, however, do not recognize advance directives and/or have difficulty enforcing them (e.g., Portugal, Italy)<sup>(7,34)</sup>

- › Religion and spirituality can influence EOL care and decision making, with various religions having specific perspectives or edicts related to EOL<sup>(18)</sup>
  - The Catholic and Christian perspectives do allow for the removal or withholding of treatment that is deemed futile if the treatment is burdensome, dangerous, or disproportionate to the expected outcome. Withdrawal of artificial nutrition and hydration is still controversial<sup>(18)</sup>
  - The Jewish perspective as it relates to life-sustaining treatment is complex and focuses on the act of omission. If the treatment requires stopping or starting (e.g., IV fluids that need to be stopped when one bag of fluid runs out and the next bag starts), the client can choose to omit the next treatment rather than withdrawing something that is continuous, such as a ventilator. Within the Jewish community, there are differing opinions regarding whether artificial nutrition and hydration should be classified as medicine<sup>(18)</sup>
  - Buddhist principles are generally against the removal of life-sustaining support unless the chance of recovery is very small. In situations with clear futility, there is leeway about the withdrawal or withholding of these treatments<sup>(18)</sup>
  - Islamic teachings focus on the sanctity of human life. Physicians are expected to do everything possible to prevent a premature death but do not have to pursue treatment in futile situations. Nutrition and hydration are considered a basic human right and are often expected to be provided<sup>(18)</sup>

## What We Can Do

- › Learn about the challenges of discussing EOL care with clients and their families and provide the necessary information to make decisions for EOL; share this knowledge with your colleagues
- › Develop an awareness of your own cultural values, beliefs, and biases and develop knowledge about the histories, traditions, and values of your clients. Adopt treatment methodologies that reflect the cultural needs of the client<sup>(4,23,31)</sup>
- › Learn and practice therapeutic communication skills, with an emphasis on honesty, empathy, cultural sensitivity, and patience. Use language that clients and caregivers can easily understand<sup>(25,27)</sup>
- › Recognize and deal with issues in EOL care and be comfortable helping individuals and their families with sensitive and potentially painful issues<sup>(15)</sup>
- › Acknowledge any possible spiritual or religious conflicts that may arise with EOL decisions<sup>(18)</sup>
- › Provide support to caregivers by recognizing their physical, emotional, and financial stresses and assessing their social supports
  - As a client's disease progresses, assess the need for referrals to social service agencies, physical or occupational therapy, home nursing care, and healthcare assistants
- › Encourage clients and their families to participate in activities they enjoy for as long as possible, to participate in religious or spiritual activities, if desired, and to avoid social isolation
- › Encourage clients to prepare for EOL while still living their lives fully through the use of an advance directive and assignment of a healthcare proxy. Encourage clients and families to share their feelings about death
- › Educate caregivers regarding bereavement support
- › Encourage caregivers to obtain more information from
  - the Conversation Project,<http://theconversationproject.org/>
  - Judy MacDonald Johnston: Prepare for a Good End,[http://www.ted.com/talks/judy\\_macdonald\\_johnston\\_prepare\\_for\\_a\\_good\\_end\\_of\\_life](http://www.ted.com/talks/judy_macdonald_johnston_prepare_for_a_good_end_of_life)
  - the National Hospice and Palliative Care Organization,[www.nhpco.org/i4a/pages/index.cfm?pageid=3254](http://www.nhpco.org/i4a/pages/index.cfm?pageid=3254)
  - Palliative Care Matters,[www.pallcare.info/](http://www.pallcare.info/)
  - Aging with Dignity,[www.agingwithdignity.org/](http://www.agingwithdignity.org/)
- › Encourage clients and caregivers to visit *Caring Connections* at <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289> to create state-specific advance directives

## Coding Matrix

References are rated using the following codes, listed in order of strength:

<b>M</b> Published meta-analysis	<b>RV</b> Published review of the literature	<b>PP</b> Policies, procedures, protocols
<b>SR</b> Published systematic or integrative literature review	<b>RU</b> Published research utilization report	<b>X</b> Practice exemplars, stories, opinions
<b>RCT</b> Published research (randomized controlled trial)	<b>QI</b> Published quality improvement report	<b>GI</b> General or background information/texts/reports
<b>R</b> Published research (not randomized controlled trial)	<b>L</b> Legislation	<b>U</b> Unpublished research, reviews, poster presentations or other such materials
<b>C</b> Case histories, case studies	<b>PGR</b> Published government report	<b>CP</b> Conference proceedings, abstracts, presentation
<b>G</b> Published guidelines	<b>PFR</b> Published funded report	

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