

Position Statement

REGISTERED NURSES' ROLES AND RESPONSIBILITIES IN PROVIDING EXPERT CARE AND COUNSELING AT THE END OF LIFE

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Status: Revised Position Statement

Originated By: Congress on Nursing Practice and Economics and Center for Ethics and Human Rights Advisory Board

Adopted By: ANA Board of Directors

Related Past Action:

1. ANA Position Statement (1994): *Active Euthanasia*
2. ANA Position Statement (1994): *Assisted Suicide*
3. ANA Position Statement (1991): *PSDA (Patient Self-Determination Act)*

Supersedes: ANA Position Statement (2003): *Pain Management and Control of Distressing Symptoms in Dying Patients*

Purpose: Nurses have always been at the bedside of dying patients. Their role in providing the highest quality of remaining life and support at the end of life for both patients and their loved ones is traditional, accepted, and expected. The nurse's fidelity to the patient requires the provision of comfort and includes expertise in the relief of suffering, whether physical, emotional, spiritual, or existential. Increasingly, this means the nurse's role includes discussions of end-of-life choices before a patient's death is imminent.

The purpose of this ANA Position Statement is to articulate the roles and responsibilities of registered nurses in providing expert end-of-life care and guidance to patients and families concerning treatment preferences and end-of-life decision making. It is meant to provide information to guide the nurse in vigilant advocacy for patients throughout their lifespan as they consider end-of-life choices, and includes discussion of personal ethical dilemmas that can occur when caring for the dying.

Statement of the ANA Position: End-of-life choices are a quality of life issue.

Nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care, including the promotion of comfort, relief of pain, and support for patients, families, and their surrogates when a decision has been made to forgo life-sustaining treatments. Throughout this Position Statement, the term “family” includes immediate relatives by blood or marriage, same-sex partners, and any others designated by the patient. While nurses should make every effort to provide aggressive pain control and symptom relief for patients at the end of life, it is never ethically permissible for a nurse to act by omission or commission, including, but not limited to medication administration, with the intention of ending a patient’s life.

Academic preparation and continuing education should prepare nurses to provide comprehensive and compassionate end-of-life care, so they can serve as advocates and resources for the patient and patient’s family. Expression of the patient’s fullest autonomy in end-of- life decision making is best honored by addressing such questions in the primary care setting and throughout the lifespan, not only when a life-threatening condition arises. End-of-life patient counseling and education are “best practices” in all health care settings, and should be encouraged systemically through rigorous practice standards and appropriate reimbursement.

History/Previous ANA Position Statements:

A. ANA Foundational Documents

Each of ANA’s three foundational documents explicitly highlights the importance of nurses providing competent, humane care for patients at the end of life. Through its professional standards and ethical precepts, nursing plays an essential role in assuring that patients experience their best possible quality of life at the end of life, and as respectful and peaceful a death as is possible.

(i) Nursing: Scope and Standards of Practice

ANA’s Nursing Scope and Standards of Practice (2004) informs society and the

nursing profession of nursing practice standards and guides the formulation of rules and regulations regarding nursing practice. Standard 12 of this document recommends *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2001) to guide practice and states “the registered nurse integrates ethical provisions in all areas of practice” (p. 39). This nexus between practice and ethics is critical to understanding the nurse’s role in providing end-of- life care and counseling.

(ii) *Code of Ethics for Nurses with Interpretive Statements*

ANA’s *Code of Ethics for Nurses with Interpretive Statements* (2001) describes the values and ethical precepts of the profession and provides guidance for nurses in their professional conduct, relationships, and decision making. The central ethical tenet directing the nursing profession is respect for persons. This respect extends to and encompasses patients, families, nurse colleagues and other team members. In addition, the Code of Ethics for Nurses emphasizes the nurse’s responsibility to advocate for the patient’s safety, comfort, and right to self-determination.

In particular, Provision 1.3 of the Code addresses the nurse’s role in helping the suffering or dying patient:

Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care. This is particularly vital in the care of patients and their families at the end of life to prevent the cascade of symptoms and suffering that are commonly associated with dying.

Nurses are leaders and vigilant advocates for the delivery of dignified and humane care. Nurses actively participate in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering (ANA, 2001, pp. 7–8).

(iii) *Nursing’s Social Policy Statement: Second Edition*

ANA's *Nursing's Social Policy Statement: The Essence of the Profession* (ANA, 2010) expresses the "social contract between society and the profession" of nursing (p. 5). As such, it provides a guide to nurses regarding their obligations to patients, the patient's family, and the community. It states:

Nursing interventions are intended to produce beneficial effects, contribute to quality outcomes, and – above all – do no harm.... [Nursing practice] includes, but is not limited to, initiating and maintaining comfort measures, establishing an environment conducive to well-being, providing health counseling, and teaching. ... [A]dvocacy, communication, collaboration, and coordination are notable characteristics of nursing practice. Nurses base their practice on understanding the human condition across the life span and the relationship of the individual, family, group, community, or population within their own setting and environment. All registered nurses are educated in the art and science of nursing, with the goal of helping individuals, families, groups, communities, and populations to promote attain, maintain, and restore health, or to experience a dignified death (pp. 15-17).

B. Additional ANA Supporting Document (i)

(i) *Hospice and Palliative Nursing: Scope and Standards of Practice*

Hospice and Palliative Nursing: Scope and Standards of Practice (ANA & HPNA, 2007) was developed by the Hospice and Palliative Nurses Association (HPNA) and ANA to "further advance the practice of hospice and palliative care and to set benchmarks for all registered nurses and advanced practice registered nurses who practice nursing within the realm of life-limiting, progressive illness or end-of-life care" (p. vii). Building on ANA's *Nursing: Scope and Standards of Practice* (2004), this authoritative specialty practice document articulates the professional parameters of hospice and palliative care nursing, while acknowledging that

individual state laws vary significantly, affecting the legal scope of such practice.

The goal of hospice and palliative care nursing “is to promote and improve the patient’s quality of life through the relief of suffering along the course of illness, through the death of the patient, and into the bereavement period of the family” (ANA & HPNA, 2007, p.1). This specialty practice resource also focuses attention on educational preparation, advocacy and ethics, professionalism, collaboration, systems thinking, cultural competence, communication and clinical judgment for hospice and palliative care nurses.

(ii) *Health System Reform Agenda*

ANA’s *Health System Reform Agenda* (2008) is an update of ANA’s collaboration with the broader nursing community in the early 1990s, *Nursing’s Agenda for Health Care Reform*, which articulates recommendations for addressing shortcomings in American health care quality, access, and systemic resource allocation. This 1991 blueprint for reform, endorsed by over 60 nursing and other health organizations, called for, among other things, a careful assessment of the “appropriateness of providing high-tech curative medical care to those who simply require comfort, relief from pain, supportive care, or peaceful death” (p. 17). This recommendation found further voice in the 2008 update, as an expanded call to:

reshape and redirect [the system] away from the overuse of expensive, technology-driven, acute, hospital-based services used in the model we now have, to one in which a balance is struck between high-tech treatment and community-based and preventive services, with emphasis on the latter (p. 9).

C. ANA Position Statements

This current position statement was developed to replace the prior ANA Position Statement:

- *Pain Management and Control of Distressing Symptoms in Dying Patients* (2003).

Related Position Statements:

- ANA Position Statement, *Active Euthanasia* (1994)
- ANA Position Statement, *Assisted Suicide* (1994)
- ANA Position Statement, *PSDA (Patient Self-Determination Act)* (1991)

Summaries of these positions statements are available at

<http://www.nursingworld.org/EthicsHumanRights>

Supportive Material: Dying is part of the normal process of living. Nurses' roles and responsibilities for care at the end of life are intensified by circumstance, but ultimately are grounded in the fundamentals of nursing ethics and practice throughout the life continuum. The counseling a nurse provides regarding end-of-life choices and preferences for individuals facing life-limiting illness, as well as throughout the patient's lifespan, honors patient autonomy and helps to prepare individuals and families for difficult decisions that may lie ahead. While often rewarding, this is demanding work that requires the nurse to marshal her or his professionalism and compassion, while honoring her or his own personal integrity.

These roles and responsibilities are addressed here in separate discussions regarding the nurse's guidance and support for patients and their families at the end of life, the standards and guidelines for competent end-of-life care-giving, the nurse's obligation to prepare educationally to provide such care, and the ethical implications and questions the nurse might face in helping patients and their families at the end of life.

A. Nurses' Guidance and Support for Patients and Families at the End of Life

Nurses should be competent in the care of patients throughout the continuum of life. This includes the obligation for nurses to help manage pain and other distressing symptoms for patients with serious or life-limiting illness, and to work with patients and their families in palliative and end-of-life care decision making.

Palliative care is generally understood as caring for those across the trajectory of serious illness, regardless of projected life expectancy. There is no consensus on a definition of what constitutes “the end of life.” Clearly, however, caring for patients with chronic and rapidly progressive disease draws heavily on palliative measures as a central part of the care plan.

At any time in their lives, and especially upon receiving a diagnosis of a serious illness, patients or their families may ask nurses for assistance in developing a palliative and/or end-of-life care plan. Nurses should seek to understand the patient’s concerns prompting the request for guidance by exploring the patient’s fears, needs, and values, discussing health care options, and providing counsel and support. The overarching ethical precept of patient autonomy should guide all discussion regarding the end of life.

In the event the patient is unable to speak for him- or herself, nurses and other health care team members should look to any health care advance directives the patient has executed to “speak” in his or her incapacity, and invite family support. The nurse does not act in a vacuum; it is important to bring in others skilled in palliative care and end-of-life issues, such as other nurses, social workers, physicians, hospice representatives, and spiritual care providers, to assist the patient and family in this decision making. The caring presence of the nurse, with additional assistance from these individuals, can ease both the patient’s and the family’s suffering.

There is a broad continuum of palliative and end-of-life choices and interventions that a patient may consider. These include measures to alleviate suffering and pain, do-not-resuscitate orders, designation of a surrogate for health care decision-making,

withdrawing or withholding nutrition and/or hydration, and the decision to forgo life-sustaining treatment. To be able to respond to patients' needs reasonably, compassionately, and ethically, the nurse should be familiar with the subtleties associated with this range of choices and interventions.

(i) *Advance care planning and counseling*

Advance directives express how the patient would want to be treated, based on her or his values and beliefs, when the patient is unable to speak for her- or himself. Some examples are living wills, do not resuscitate orders, durable powers of health care attorney, and other health care proxies. Many people, including some health care professionals, believe that the requirements of advance care planning are satisfied by the patient completing an advance directive. Indeed, while such documents are important care decision-making tools at the end of life, they are ideally the end product of a process of conversations and decisions that the patient has made, while still having decision-making capacity, with his or her health care provider, family, and perhaps spiritual care provider, legal counsel, or others.

Whether discussions are initiated in the outpatient or acute care setting, the first step is listening, a skill in which nurses excel. The goal is:

... to find out how well the patient and family understand the patient's relevant medical conditions, and what their expectations, hopes, and concerns are. This listening phase can provide insight into the patient's values and goals and how much the patient and family want to engage in these discussions (Messinger-Rapport, 2009, p. 277)

Advance care planning discussions are initiated optimally in the outpatient setting. It is typical for patients with advanced chronic illness to receive care in outpatient settings at some point during their last year of life. Specialists and generalists must be equally engaged, however, and not have the expectation that one or the other is

responsible for providing such discussions, because care for certain patients may be delivered primarily in either practice setting (Lorenz et al, 2005). Coordination of these efforts is especially important with patients suffering from conditions such as advanced cancer, dementia, HIV/AIDS, end stage renal disease, and chronic heart failure.

During an office visit, the nurse or other provider can seek opportunities to explore care preferences with patients, answering questions and providing materials for patients to take home to review and discuss with family members. It is essential to follow up during future visits. Family or surrogates may be included, with the patient's permission. After completing appropriate documents, the patient can review them with the health care provider, make any changes, and receive assurance that her or his wishes will be available in the health care record when needed. (Emanuel, 1995) Ideally, the patient's documented preferences should also be reviewed upon admission to and discharge from any acute care setting.

Advance care planning is a process; therefore multiple visits are typically more useful than a one-time description of available advance directives. Discussing goals of care and prognosis is a necessary first step in this process, building a foundation on which any patient can consider which treatments they may or may not want. End-of-life research physician Joan Teno, of Brown University's Center for Gerontology and Health Care Research, succinctly described the goals of advance care planning more than a decade ago:

- Ensure clinical care consistent with patient preferences when capacity is lost.
- Improve decision-making process.
- Facilitate shared decision-making process.
- Allow proxy to speak on behalf of patient.
- Respond with flexibility.
- Provide education.

- Improve patient's well-being by reducing frequency of overtreatment or undertreatment.
- Reduce patient's concern regarding possible burden placed on family and others (Respecting Choices®, History, ¶ 9, 2008).

These goals are filtered largely through the clinician's perspective, reflecting earlier thinking about advance-care planning. More recently, some authors (Kolarik, Arnold, Fischer and Tulsy, 2002, for example) argue that there is no consensus on the objectives for advance-care planning; yet they simultaneously note that there is a broad diversity of outcomes that patients and their providers may seek with advance care planning. They conclude that:

... Health care providers, patients, and surrogates should identify and agree on common objectives for particular conversations. Various methods, conversations, and forms may be used to achieve these objectives over time. Clarifying objectives from various perspectives is an important step toward achieving the level of understanding necessary to make these difficult decisions (p. 697).

Respecting Choices®, a nationally recognized end-of-life program in LaCrosse, Wisconsin, describes advance care planning, more through patients' eyes, as "the process of coming to understand, reflect on, discuss and plan for a time when you cannot make your own medical decisions" (Gunderson Lutheran Medical Center, 2000, p. 5). Its patient booklet continues, "Effective planning is the best way to make sure your views are respected by your loved ones and health providers. This process also will provide great comfort to those who may make end-of-life decisions for you" (p. 5). Nurses are central to the Respecting Choices model, in providing individual care counseling, as well as education at the institutional, systems, and community levels.

Another initiative to enable patients to explore and document their preferences for end-of-life care is the Physician (or Provider) Order for Life-Sustaining Treatment (POLST).¹ This program, started in Oregon in 1991 and adopted by many states, is designed “to improve the quality of care people receive at the end of life. It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health care professionals to honor these wishes” (POLST, ¶ 1, 2008). The POLST process includes “ongoing training of health care professionals across the continuum of care about the goals of the program as well as the creation and use of the form” (POLST “Program Requirements,” 2008).

The POLST form constitutes a set of medical orders; therefore, it must be signed by a physician or, depending on the state, a nurse practitioner, in consultation with the patient or the patient’s surrogate. The form includes concise directions concerning the types of interventions a patient may or may not want, such as resuscitation, decisions about transport, ICU care, artificial nutrition, therapeutic measures to promote comfort (e.g., antibiotics, oxygen, skin care), and such. It should be reviewed periodically and can be modified or revoked at any time. Consult the POLST website (www.polst.org) to see the most up-to-date list of which states use the POLST form. Each state’s form and program is different, due to differences in state laws and regulations.

Nurses can work with other available tools, such as the Respecting Choices “Making Choices Planning Guide” (Gunderson, 2000), the Aging With Dignity organization’s “Five Wishes” materials (2009), or personal values histories, to initiate a gentle conversation to delineate wishes as one considers treatment choices or approaches the latter part of life. It is important to understand that, while these various tools are helpful in establishing the desires of patients, they are not the same as state-specific advance directives that carry the force of law. For such state-specific legal advance directives, it is advisable to consult a website that carries such information, such as the site for

¹ In some states, it is referred to as MOLST (Medical Orders for Life-Sustaining Treatment).

National Healthcare Decisions Day: <http://www.nationalhealthcaredecisionsday.org/>.
Other Web-based resources are noted at the conclusion of this Statement.

(ii) *Refusing, withholding, or withdrawing life-sustaining treatment*

Honoring a patient's refusal of treatments is ethically and legally required. Withholding or withdrawing life-sustaining treatments that are disproportionately burdensome to the patient, or that will not benefit the patient, is ethically and legally permissible. If it is legally and ethically required to respect the patient's informed consent or assent, then the patient's lack of consent should be equally binding (Dickey, 2006). Within this context, withholding or withdrawing life-sustaining therapies is ethically acceptable and does not constitute assisted suicide or euthanasia (Schwarz, 2007). The United State Supreme Court, in the 1990 case of Nancy Cruzan, confirmed that there is no ethical or legal distinction between withholding or withdrawing treatments (Cruzan v. Director, Missouri Department of Health, 497 US 261).

It is essential to understand that the withdrawal of specific therapies does not mean withdrawal of care. It is not "giving up" on the patient. The patient and family will be cared for with dignity and comfort, and appropriate palliative care measures will be made available.

Prior to the advent of newer, more effective medical technologies, and in an era when medicines were marginally effective, forgoing treatment was only peripherally associated with the patient's death; a disease simply ran its natural course (Jonsen, 2005). With the introduction of advanced life-sustaining technology, ceasing these treatments might appear to bring about death. However, in 1988, the American Medical Association and British Medical Association each officially recognized that it is ethical and legal to forgo life-sustaining treatments for patients who are terminally ill, with the patient's consent or authorized proxy (Jonsen, 2005).

An articulate patient with decision-making capacity can request the withdrawal of treatment directly. A patient who lacks decision-making capacity can also express a

desire for withholding or withdrawal of treatment through written instructions in an advance directive or health care proxy. All the various forms of advance directives should be honored as the patient's direct wishes. In a Presidential Memorandum of April 15, 2010, President Barack Obama requested federal rulemaking to reinforce existing regulations – 42 CFR 482.13 and 42 CFR 489.102(a) – that “all patients’ advance directives, such as durable powers of attorney and health care proxies, are respected” in all hospitals receiving Medicare or Medicaid funding (Presidential Memorandum, ¶ 7, April 15, 2010).

Rather than Do Not Resuscitate (DNR), the nurse may encounter the terminology of an Allow Natural Death (AND) order. Allow Natural Death was developed as a positive statement, emphasizing the commitment to patient and family that the loved one will be cared for and supported in dying with compassion and dignity. Within the statement is the promise that no technological interventions will be used to prolong life and possibly increase suffering (Cohen, 2004).

When a patient who lacks decision-making capacity appears to demonstrate more burden than benefit from active treatment, or does not improve after trials of treatment, a designated surrogate/proxy may generally request that treatment be withdrawn, based upon his or her knowledge of the patient's wishes in such circumstances. This is most reliably accomplished through a durable health care power of attorney, wherein a surrogate decision-maker is named and often is provided guidance by the patient while he or she still retains decision-making capacity. Lacking such a formally designated person, state law varies on who has precedence in representing the patient's interests. The health care facility's legal office can provide any needed guidance to the health care team.

None of these documents is completely fail-safe. It is difficult for an individual, even in consultation with a knowledgeable health care provider, to fully grasp the considerable array of circumstances and options that might attend his or her final days or hours. It is even more difficult for a written document to completely cover every possibility.

Therefore, nurses, other health care providers, families and health care surrogates may be in the position of trying to discern what the patient would have wanted, based on the evidence available.

For example, a “living will” usually addresses life-sustaining treatments such as dialysis, mechanical ventilation, and medically supplied nutrition and hydration. This instrument is less likely to provide guidance on interventions for a patient with dementia, “such as intubation to get through an episode of potentially reversible respiratory failure, a feeding tube to correct weight loss, or cardiac catheterization or bypass surgery to treat angina. Yet these important decisions often arise as function declines and comorbidities progress” (Messinger-Rapport, 2009, p. 278).

While this may be challenging for nurses, there are methods of respecting DNR/AND orders for patients undergoing palliative surgery. All who are involved in the care—including families—must engage in a hospital-supported process of non-coercive, shared decision making, where discussions are most helpful if focused on what will be done for the patient rather than what will not be done. Conclusions must then be shared with all pertinent staff and respected, even if staff disagrees with the treatment plan. In that case, a request to transfer care to another member of the health care team is appropriate, if possible (Berlandi and Duncan, 2008). (See also, section 4Dv. of this document, regarding moral distress.)

(iii) *Palliative care and hospice services*

The goal of *palliative care*, as defined by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP), is

both a philosophy of care and an organized, highly structured system for delivering care. The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the

disease or the need for other therapies (NCP, 2010c, “What is Palliative Care,” ¶ 1).

The traditional medical model of serious illness or dying did not include the goals of “enhancing quality of life for patients and family members, helping with decision-making, and providing opportunities for personal growth” (NCP, 2010c, “What is Palliative Care,” ¶ 1). The emergence of palliative care as a field of intensive research, study, and care delivery has rendered this model obsolete.

As a care delivery model, palliative care is characterized by an interdisciplinary team approach that includes “medicine, nursing, social work, chaplaincy, counseling, nutrition, rehabilitation, pharmacy, therapists, and other health care professions” (NCP, 2010c, “What is Palliative Care,” ¶ 2). In addition to addressing a patient’s medical needs, it is designed to:

... identify and address the physical, psychological, spiritual, and practical burdens of illness. Palliative care affirms life by supporting the patient and family’s goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. (NCP, 2010c, “What is Palliative Care,” ¶ 2)

In order to meet current and future needs for palliative care, educational opportunities must be available for nurses and other health care professionals to acquire the necessary knowledge and skills regarding principles and practice of palliative care. Nurses can also pursue academic programs or other learning opportunities to prepare them to specialize in palliative care in various settings (NCP, 2010c).

Hospice is a philosophy of care, a spectrum of services, and sometimes a particular location for services. Starting hospice care is not the end of hope but rather a change in

focus for patients (Jennings, Ryndes, D'Onofrio and Baily, 2003). Additionally, it reflects a change in goals of care to maximize the patient's and family's comfort and dignity with appropriate palliative care measures. Hospice provides professional nursing care, assistance with activities of daily living, and various services, from dietary support to spiritual and psychological counseling. It also makes available medications, devices, oxygen, and hospital beds for use in the home or other facility. Nurses and other members of the hospice team provide family bereavement follow-up. Since the preferences and situations of hospice patients is so widely varied, nurses must be prepared to work with people of all income levels, in homes, apartments, boarding houses, prisons, and on the streets.

Eligibility for the Medicare hospice benefit currently requires certification by a physician and the hospice medical director that, in their clinical judgment, the person is terminally ill and has 6 months or less to live if their illness runs its "normal course" (Certification of Terminal Illness, 42 CFR 418.22, 2004). Some patients become concerned that they will "outlive" their benefit and therefore delay seeking appropriate hospice services. However, if the individual does not die within 6 months, his or her hospice certification can be continually renewed every 60 days.

The law also allows individuals who were discharged because they were no longer terminally ill to elect hospice care again if their condition is again evaluated to be terminal. Regardless of their election of hospice for care of their terminal illness, they still retain their Medicare coverage for conditions not related to the terminal illness. The challenge is almost never that an individual has lived beyond 6 months after entering hospice. It is that patients and their families wait too long to take advantage of the care and services offered. The average number of days that an individual stays in hospice before death is reported variably, depending on facility and illness, but is generally 40 days or fewer [MedPAC, 2008].

(iv) *Assisted suicide and euthanasia*

Patients or their designated surrogates/proxies may find the end-of- life condition hard

to endure or imagine. Patients often wish to be in control of their lives and to state their wishes concerning their treatment preferences for end-of- life care. Patients asking for assistance in dying—or assisted suicide—may, in reality, be voicing their desire for autonomy, pain relief, a release from existential despair, emotional support, nursing presence, support for their families, and/or spiritual sustenance. The nurse must be able to recognize a patient’s needs that may be cloaked in a request for assistance in dying. ANA’s *Code of Ethics for Nurses* clearly states, however, that “nurses may not act with the sole intent of ending a patient’s life, even though such action might be motivated by compassion, respect for autonomy and quality of life considerations” (2001, p. 8).

In 2010, Oregon, Washington, and Montana are the only three states where physician aid in dying has been legalized. Several other states have considered or are considering similar proposed legislation related to this issue. Active euthanasia is illegal throughout the United States.

Regardless of the legality of the issue, it is essential for nurses to understand that the ANA *Code of Ethics for Nurses* expressly forbids the intentional taking of human life. The issues of assisted suicide and euthanasia are discussed in greater length in ANA’s related Position Statements, *Assisted Suicide* and *Active Euthanasia*.

B. Standards and Guidelines for Competent End-of-life Care Giving

Empirical research into what factors are associated with better or poorer end-of- life care and outcomes is limited, but growing. Based on the research that has been pursued thus far, many public and private entities have sought to translate these outcome domains and measured variables of care into standards that the nurses and other health care professionals can use in providing palliative and end-of- life care and counseling. A few of the more prominent efforts, particularly as they relate to nursing standards and practice, are noted here. Further resources are noted at the end of this document.

(i) *National Consensus Project Clinical Guidelines for Palliative Care*

The National Consensus Project (NCP) represents the collaboration among four organizations: the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association (HPNA), and the National Hospice and Palliative Care Organization (NHPCO). It has developed and disseminated Clinical Practice Guidelines for Quality Palliative Care, the latest version in 2009 (NCP, 2009).

A major objective of the NCP is to “heighten awareness of palliative care as an option in treating those with a life-limiting or chronic debilitating illness, condition or injury, and to raise public understanding of the growing need for such care.” (NCP, 2010a, ¶ 1). These guidelines are the basis for the National Quality Forum (NQF) Preferred Practices and have become “a hallmark within the field guiding policy makers, providers, practitioners and consumers in understanding the principles of quality palliative care.” (NCP, 2010b, ¶ 1).

The guidelines describe core precepts and structures of clinical palliative care programs and are divided into eight major sections:

- Structure and Processes of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care

These elements may be reviewed online in greater detail in the NQF’s full report, National Framework and Preferred Practices for Palliative and Hospice Care Quality. (NQF, 2006).

(ii) Agency for Healthcare Research and Quality (AHRQ)

The Agency for Healthcare Research and Quality (AHRQ), housed within the U.S. Department of Health and Human Services, sponsors, conducts, and disseminates research to help people make more informed decisions and improve the quality of health care services. Upon review of the end-of-life care literature, they concluded that there is evidence that patient satisfaction with the quality of care at the end of life is “related to pain management, communication, practical support, and enhanced caregiving” (AHRQ, 2004, p. 25). These elements speak directly to nursing care.

In its comprehensive guide, *Advance Care Planning: Preferences for Care at the End of Life*, the Agency continues:

... In the best of circumstances, the patient, the family, and the physician have held discussions about treatment options, including the length and invasiveness of treatment, chance of success, overall prognosis, and the patient's quality of life during and after the treatment. Ideally, these discussions would continue as the patient's condition changed (Kass-Bartelmes, BL, Hughes, R and Rutherford, MK, 2003, ¶ 7).

All of these are essential nursing functions and are reflected in *Hospice and Palliative Nursing: Scope and Standards of Practice* (ANA, 2007).

(iii) National Institutes of Health (NIH) and Institute of Medicine (IOM)

The NIH has convened multiple expert panels and symposia seeking to identify, and where possible, quantify the elements of expert care at the end of life. Its 2004 conference on Improving End-of-Life Care, for example, identified a dearth of consistently used or validated measures in the subject area and sought to articulate a research agenda for the future improvement of care (NIH, 2004, p. 20).

The Institute of Medicine (IOM, 2003) has examined data to evaluate the quality of life and quality of care experienced by Americans at end of life. IOM found “convincing evidence that for a significant proportion of Americans” the goals of good end-of- life care are not being met. IOM suggests creating more benchmarks to measure the success of good end-of- life care (IOM, 2003).

C. Nurses’ Obligation to Prepare Educationally to Provide Competent End-of-Life Counseling and Care

Meeting the physical, psychosocial, and spiritual needs of the patient, and continuing dialogue related to advance care planning, are essential to improving the end-of- life experience for patients and families (Heidrich, 2007). It is essential that nurses acquire the necessary competencies, through their academic preparation and continuing education, to effectively guide and advocate for patients and families in end-of- life planning the dying process itself.

The Essentials of Baccalaureate Education for Professional Nursing Practice, published in October 2008 by the American Association of Colleges of Nursing (AACN), addresses this specific issue. Under “IX, Baccalaureate Generalist Nursing Practice,” Number 6 calls for programs to “implement patient and family care around resolution of end-of- life and palliative care issues, such as symptom management, support of rituals, and respect for patient and family preferences (AACN, 2008, p. 31). This standard should be adopted in all nursing education, from diploma nurse programs through the BSN and advanced degree programs and certifications.

The End-of-Life Nursing Education Consortium (ELNEC), developed by the American Association of Colleges of Nursing (AACN) and the City of Hope National Medical Center, under a grant from the Robert Wood Johnson Foundation, is one of the more commonly adopted nursing education programs throughout the country. In the ELNEC curriculum, nurses learn specialized content in nine areas:

- Care at the end of life
- Pain management
- Symptom management
- Ethical and legal issues
- Cultural considerations
- Communication
- Grief, loss, and bereavement
- Achieving quality care at the end of life
- Preparation and care for the time of death

However, the scope of ELNEC can and should grow to embrace the larger ethos of advance care planning and counseling as a part of primary care, in addition to its clear place in the acute and hospice settings (AACN, 2009). More information is available online regarding this valuable program at <http://www.aacn.nche.edu/ELNEC/>

In addition to academic programs, nurses can seek continuing education opportunities to gain or expand their knowledge and skills in providing end-of-life care. Such opportunities are increasingly offered for staff in residential and inpatient facilities, sponsored by in-house specialists or outside groups. The National Hospice and Palliative Care Organization (NHPCO) is one of many groups that offer continuing education for nurses, physicians, social workers, and counselors through direct programming, webinars, and other media.

D. Ethical Considerations

An ethic of care permeates and underscores all of professional nursing practice. Caring is relational and takes place in the context of the nurse-patient relationship, the respectful and genuine presence of one human being with another. The nurse's presence is extended to the patient and family in these difficult times. Nurses are called on to initiate discussions with patients and families regarding cultural practices and preferences, to assure that these beliefs are respected both before and after the patient's death.

The principles of autonomy (self-determination, right to privacy), beneficence (doing good), nonmaleficence (doing no harm), veracity (truth-telling), confidentiality (respecting privileged information), fidelity (keeping promises), and justice (treating people and allocating resources fairly) are all understood in the context of the overarching commitment to respect for persons (ANA, 2001). Nurses are challenged to uphold these principles as they confront the realities of professional practice.

The Code of Ethics for Nurses states that respect for persons "extends to all who require the services of the nurse for the promotion of health, the prevention of illness, the restoration of health, the alleviation of suffering, and the provision of supportive care to those who are dying" (ANA, 2001, p. 7). This respect encourages nurses to ask such questions as:

- What is "right" thing to do?
- What are the benefits and burdens of this action?
- Who should be making this decision?

(i) *Autonomy*

Nurses support, advocate, and value patient autonomy in decision making in a health care environment. Frequently they must set aside their own personal preferences to enter into meaningful conversation with patients and their families. Though there is a profound commitment both by the profession and the individual nurse to the patient's right to self-determination, limits to this commitment do exist. In order to preserve the moral mandates of the profession and the integrity of the individual nurse, nurses are not obligated to comply with all patient and family requests. The nurse should inform the patient and family when unable to follow a specific request and explain the rationale for that decision.

Autonomy is viewed differently by different cultures—so, for example, a patient or family member may ask that the patient be shielded from information about his or her illness. Nurses can make sure that all members of the health care team know that this

is the patient's choice. Another reality of patient decision making is that people can change their minds; decisions can be changed. Nurses and others must remember to offer patients the opportunity to consider changes in any health care plan.

(ii) Competence/ Capacity

Competence is a legal construct. *State laws recognize that adults (almost uniformly defined as age 18 or older) have the right to make their own health care decisions. Clearly,* infants and small children are unable to participate meaningfully in their own health care decisions. In such situations, decision-making is left to their parents or legal guardians. The age at which a child attains competence differs among states' laws, and is also addressed by federal regulations. The courts and state law generally recognize the "mature minor" doctrine, acknowledging that a child's age, maturity, conduct, and other factors can be evaluated as to whether the child has the ability to participate meaningfully in his or her own health care decisions (Costello, 2008). There are also federal regulatory requirements for the participation of minors in health research, and for providing assent, consent, or dissent to participate in health care decisions about their own bodies (Additional Protections for Children Involved as Subjects in Research, 1983; OHRP, 2010).

While related, the concept of capacity is different from that of legal competence. Capacity, generally speaking, is the patient's ability to understand the clinical facts and consequences of his or her health status and care alternatives and, further, to make decisions regarding her or his care (Hamilton, 2001). This is most often assessed by clinical care providers, in conversation with the patient and consultation with the family, and in some cases, with psychiatrists or other specialists. Nurses should be aware that it is possible for a patient's capacity to be compromised over time based on variables such as medical condition, age, medication, lack of sleep, and general mental acuity. Careful observation and consultation may be called for. Factors such as eccentricity, being querulous, unkempt, or having certain diagnoses do not necessarily diminish capacity. Scheduling discussions for when patients are not tired or in pain will contribute to increasing their capacity to make good decisions.

(iii) *Justice*

Nurses must examine these issues not only from the perspective of the individual patient, but from the societal and professional community perspective. Involvement in community dialogue and deliberation will allow nurses to recommend and uphold initiatives, and provide leadership in promoting optimal end-of- life care.

Currently, federal reimbursement and most insurance plans do not pay health care providers for the time and multiple sessions required to proactively discuss these sensitive, many-faceted issues with patients. Unfortunately, this can create a financial drain on those who seek to provide such services. The example of payment for other necessary patient interventions is informative: when both public and private reimbursement were allocated for tobacco cessation counseling, the ability of many primary care practices to provide such services rose significantly, helping countless patients (Theobald & Jaen, 2006; CMS, 2005). Similarly, counseling patients on end-of-life issues should be part of such best practices, especially for primary care providers. Expression of the patient's fullest autonomy in decision making could best be honored by addressing such questions at the primary care level and throughout the lifespan, not only when a life-threatening condition arises.

The ethical principle of justice is often used as a framework for discussing issues related to resource allocation within the health care arena. Nurses recognize that palliative care and hospice services are, for many patients, a better choice than attempts at high-tech curative care. It is not uncommon for the burdens of treatment to outweigh the benefits; such circumstances call for an honest and compassionate discussion with the patient who has capacity, or with the surrogate decision maker, about the patient's preferences regarding their perceived quality of life. Regardless of her or his good intentions, it is not appropriate for the nurse to usurp these decisions from the patient or surrogate. At both the local and national levels, nurses must assume a leadership role in advocating for legislative or other initiatives that ensure adequate

funding of appropriate end-of-life care.

(iv) *Beneficence and nonmaleficence*

“Doing good” or “doing no harm” are constant challenges when working with patients throughout the life cycle, and are especially pertinent as the patient nears the end of life. Good communication that emphasizes listening is a fundamental tool to help patients and families with end-of-life decisions.

Families and/or significant others caring for their dying loved ones need to be informed about what to anticipate during the dying process and at the time of actual death. Further, nurses should help prepare the family on steps to be taken and who must be contacted if the patient dies at home. This is especially important if hospice is not called in to assist. Providing this critical education will help to reduce the amount of fear and anxiety frequently associated with “not knowing” (Heidrich, 2007). Nurses can improve the quality of the caregiver’s experience with the death of a loved one by initiating honest, open, and compassionate discussions concerning the realities of the dying process.

Individual preferences often vary among cultures. (Culture here can refer to ethnicity, religion, race, gender, age, sexual orientation, and many other characteristics). It is up to the nurse to recognize and respect cultural differences when they are present. Some examples of how cultural differences play out may be shared or deferred decisions instead of individual decisions; preference for providing complete information rather than keeping some information from the patient; or the patient trusting the health care team and family to do what is best, rather than independently making personal decisions about treatment preferences and goals of care.

A patient may experience a significant decrease in his or her quality of life because of increasingly distressing physical symptoms. Equally important, but often inadequately managed, are the patient’s psychosocial symptoms, including

depression, anxiety, a sense of loss, grief, isolation, spiritual distress, and being a burden to loved ones; these can negatively affect his or her end-of- life experience (Heidrich, 2007). The nurse can enhance the patient's quality of life throughout the dying process through expert assessment and implementing interventions that ameliorate the patient's symptoms, both physical and psychosocial.

(v) *Moral distress*

Nurses report that they become increasingly uncomfortable in situations that challenge their moral values, and frequently feel compromised by wanting to do the "right thing" while fearing the results of doing so. (Schwarz, 2003).

Steinhauser, et al (2000) found that patients who were seriously ill identified freedom from pain, being at peace with God, family presence, cognitive awareness, and respect for treatment preferences as most important to them. Palliative care teams can work with the patient and family to provide an appropriate level of pain relief, maximizing the opportunity for the patient to communicate with family.

As the patient's functioning declines, he or she may become increasingly dependent upon family and health care providers for emotional, as well as physical support. Providing care to the dying can be an overwhelming experience for all involved. The nurse's expertise, advocacy, and compassion can make the patient's and family's experience more comfortable. These same skills are essential to the nurse's collaboration with the interdisciplinary health care team as it considers the dying patient's plan of care. Individuals and their families can make these decisions with more confidence when nurses and other health care professionals have provided education, guidance, and support throughout the lifespan, not only as the end of life nears.

Disagreements may arise among family members, the health care team, or both. In these cases, a facility's Ethics Committee can be a resource. It is prudent to acknowledge charged emotions, such as anger, fear and frustration, and allow them

to be expressed. The nurse can help identify the appropriate decision makers, provide and clarify any relevant information, then remain objective, and support whatever decision is made.

This is not always an easy balance. For example, individuals who are sometimes closer to the patient than family members can be excluded from such discussions, by intention or omission. The Presidential Memorandum of April, 2010, in addition to requiring hospitals to honor advance directives, requests further rulemaking to “ensure that hospitals that participate in Medicare or Medicaid respect the rights of patients to designate visitors,” and that these designated visitors have visitation rights “no more restrictive than those the immediate family enjoy” (Presidential Memorandum, April 15, 2010, ¶ 6). It requests recommendations addressing discrimination regarding “hospital visitation, medical-decision-making and other health care issues that affect LGBT [lesbian-gay-bisexual-transgender] patients and their families” (Presidential Memorandum, April 15, 2010, ¶ 8). Thus, nurses should know that same sex partners, unmarried partners, or close friends may provide surrogate decision making, and in any case, cannot be barred from any visitation rights that family members enjoy.

Nursing curricula should include exploration of the individual student’s values in the context of death and dying, to better prepare them to serve the patient’s best interests in their professional role as guide and advocate. Should the nurse’s moral values conflict with the ability to counsel individuals regarding end-of-life care decisions or to provide care for patients at the end of life, this must be identified early in her or his career in order not to compromise the nurse’s or the patient’s values.

Nurses must identify and seek opportunities to demonstrate their lasting commitment to patients and families within the confines of professional practice. Their efforts should be directed toward implementation of programs of palliative care to better manage the chronic, severe bio-psychosocial and spiritual distress that limit patients’

quality of life and increase their suffering. Nurses are obligated to avoid abandonment of patients and to listen compassionately to patients' requests, while recognizing the boundaries of acceptable ethical nursing practice.

Nurses' spiritual beliefs are, of course, varied. Grant (1997) suggests that there are several "theological reflections" to consider in examining the issues surrounding impending death. These include personalism, community, a search for new images of God, spirituality, and the acknowledgment of human mortality, the explorations of which help to create safeguards guided by moral consciousness. Other theological reflections may include valuing and respecting a person's autonomy, identifying new ways of caring for one another, understanding that individuals yearn for a sense of meaning and purpose in their lives, and being aware that despite technological and scientific advances, death is part of the human condition. These are many of the same considerations that comprise a more secular reflection as well.

(vi) *Care for the caregivers*

Nursing is a stressful profession. Caring for a dying patient may intensify the nurse's emotional distress, just as it does for the family and loved ones. "The need for self-care becomes an essential task for the professional, rather than merely a beneficial exercise" (Brabant, 2001, p.443). Nurses witness firsthand the devastating effects of debilitating and life-threatening disease and are often confronted with the despair and exhaustion of patients and families. They may experience feelings of sadness, fear, discouragement, and helplessness; it is important to recognize that these feelings may influence clinical decision making. Burnout and compassion fatigue are real risks, and can be ameliorated through social support, physical self-care, and other avenues.

Nurses should seek the expertise and resources of organizations that work with end-of-life issues. Others who can expand and clarify knowledge about death and dying include nurse colleagues, health care team members, pastoral services, hospice specialists, and ethics consultants/committees. Helpful Web-based resources are

listed at the end of this document.

Nursing must seek ways to support an enriching dialogue on death and dying, and help diminish the culture of secrecy surrounding the topic

Recommendations: The debate and controversy surrounding assistance in dying have highlighted the shortcomings of the health care system—in particular, care for the dying and education of health care providers and the public on end-of-life care and the dying process. The goals for nurses' advocacy around end-of-life issues, in practice, education, research, and administration are:

Practice

1. Advance the precepts of ANA's *Health System Reform Agenda* (2008) and its earlier (1993) version, *Nursing's Agenda for Health Care Reform*, which called on nurses to advocate for reshaping the health care system in a way that permits careful assessment of the "appropriateness of providing high-tech curative medical care to those who simply require comfort, relief from pain, supportive care or peaceful death" (ANA, 1992, p. 17).
2. Contribute to professional and public dialogue and decision making on death and dying, with nursing participating in these discussions at local, state, national, and global levels.
3. Collaborate with members of other health professions and the community to advance and assure the availability of quality end-of-life care.
4. Work to remove barriers to delivering appropriate end-of-life care. These include, but are not limited to, the lack of provider reimbursement for advance care planning with patients, restrictive legislative and regulatory provisions, and institutional practices.

5. Encourage patient and family participation in health care decision making, and the use of advance directives and/or designation of a health care surrogate or proxy.

Education

1. Use the End of Life Nursing Education Consortium (ELNEC) as a resource.
2. Increase nursing education in academic and service settings on providing dignified and supportive end-of-life care and counseling to all patients, prospectively and at the end of life.
3. Educate health professionals and the community on ethical and legal rights and responsibilities surrounding health care decision making, treatment options, pain control, symptom management, and palliative care.
4. Advocate for additional education in academic programs and work settings related to palliative care, the dying process, necessary measures to provide comfort at the end of life, and supporting patients and families in considering end-of-life care preferences.

Research

1. Support the use of outcome measurements and further research to ensure more evidence-based, responsible, and ethically sensitive treatment and discussions of treatment options at the end of life.
2. Develop best practices to assess the quality and effectiveness of the counseling and care patients receive regarding their end-of-life treatment and care decisions.

3. Support research that examines the relationship of patient and family satisfaction and their utilization of health care resources in end-of-life care choices.

Administration

1. Promote work environments that support ethical reflection and decision making.
2. Encourage facilities and institutions to support the clinical competence and professional development that will help nurses provide dignified and compassionate end-of-life care.
3. Reimburse providers for assisting with advance care planning and end-of-life counseling throughout the patient's lifespan.

Summary: Nurses need to remain in the forefront as leaders and advocates for the delivery of dignified and humane end-of-life care. They must be prepared to provide compassionate guidance and support for patients and their families in making quality of life choices throughout the lifespan, especially those pertaining to the end of life. They are obliged to provide comfort, relief from suffering, and when possible, a death that is congruent with the values and desires of the dying person. At the same time, nurses must uphold the ethical mandates of the profession and not participate in interventions that are directed solely toward ending a person's life.

Knowledge of the ethical foundations and parameters of professional practice provides guidance and support to nurses, both individually and collectively, better preparing them to deal with the professional challenges of the issues of death and dying. The profession has a responsibility to advocate for the importance of changes in nursing practice, education, research, and administration that will improve care at both the individual and the systems level and ensure quality of care at the end of life.

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Appendix

Resources

In the interest of providing a global resource for nurses on the issue of advance care planning and quality of care at the end of life, the following Web resources are provided. They are not meant to express the totality of resources available, but rather to guide the reader to some of the more commonly accessed Web sites on the issues presented in this Position Statement.

Caring Connections

<http://www.nhpco.org/i4a/pages/index.cfm?pageid=3254&openpage=3254>

Includes some helpful end-of-life brochures:

<http://www.caringinfo.org/resouces/brochures.htm#eolcare>

<http://www.caringinfo.org/UserFiles/File/UnderstandingtheDyingProces.pdf>

http://www.caringinfo.org/UserFiles/File/PDFs/Conversations_booklet.pdf

Compassion and Choices

<http://www.compassionandchoices.org/>

Includes state-specific advance directive toolkit, “conversation starters” for difficult discussions with family and health care providers, and links to many Web resources.

End-of-Life Nursing Education Consortium (ELNEC)

<http://www.aacn.nche.edu/ELNEC/>

Growth House, Inc.

<http://www.Growthhouse.org>

This award-winning portal is an international gateway to resources for life-threatening illness and end-of-life care. “Our primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Our search engine gives you access to the Internet’s most comprehensive collection of reviewed resources for end-of-life care.”

Guided Care: A New Nurse-Physician Partnership in Chronic Care

http://www.springerpub.com/prod.aspx?prod_id=44119

Hospice and Palliative Nurses Association

<http://www.hpna.org/>

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP)

http://www.nationalconsensusproject.org/Guidelines_Download.asp

National Hospice and Palliative Care Organization

<http://www.nhpco.org/templates/1/homepage.cfm>

Includes a fairly expansive list of links to other end-of-life resources:

<http://www.nhpco.org/i4a/links/?pageid=3287&showTitle=1>

Respecting Choices

http://www.respectingchoices.org/research_about.asp