

Palliative Care, Hospice Care, and Bioethics

A Natural Fit

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Ethical issues at end of life are not primarily medical or science issues but social, legal, religious, and cultural. This article will provide a background for addressing ethical dilemmas in palliative and end-of-life care from a mainly Western perspective. Attention is paid, however, to misunderstandings and conflicts that may arise in today's multicultural societies where values and norms differ. Examples of federal and state law that support patient autonomy and various theories of bioethics deliberation will be given. Guidelines will be provided on steps to analyze situations seen as ethically challenging. A case will be used to illustrate the role of the nurse in the decision-making process in a woman without capacity at end of life.

KEY WORDS

bioethics, hospice, nursing, palliative care

ursing is based on an ethic of care and caring. In no area is this more evident than in the care of those with progressive debilitating disease and those at the end of life. This is the first of a series of articles to be published in the Journal of Hospice & Palliative Nursing that will address some of the ethical issues that nurses encounter daily while providing palliative and hospice care. The goal is to provide a background for addressing ethical dilemmas in palliative and end-of-life nursing care. Later articles will address specific ethical dilemmas in detail. These ethical dilemmas will be ones that have been identified by palliative care and hospice nurses. Providing compassionate and ethical care has become increasingly complex and ethically challenging. In an era where advances in science and medical technology have provided the means to prolong life or in some cases prolong the dying process, the nurses' moral compass may be challenged. In addition, we live in societies that have become increasingly multicultural and complex. As a result, ethical issues that arise toward the end of life are often fraught with difficulty. They are individual and personal, as well as societal. 1,2

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The author has no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000032

Clinical ethics is a practical discipline that provides a structured approach for identifying, analyzing, and resolving ethical issues in clinical care.^{3,4} Commonly cited examples of such issues are continued life supports not perceived to be in the best interests of the patient; withholding or withdrawing treatment (most end-of-life care involves such decisions either implicitly or explicitly); inadequate communication about end-of-life care between providers, patients, and families; inadequate staffing or staff who are not adequately trained to provide required care; inadequate pain relief for patients; false hope given to patients and families; loss of capacity for patients to make their own decisions as life draws to a close; and advance directives either not present or not honored. Many of these issues will be addressed in later articles. Health care decisions that patients make are deeply personal and variable; decisions may change over the course of an illness trajectory.²

Although the issues that fall under the rubric of bioethics doing good, avoiding harm, respecting people and their communities, and justice—are of concern to every culture and society, how they are conceptualized is grounded in the moral traditions and philosophy of a particular society and culture. In other words, bioethics develops in a particular culture and fits that culture and traditions. The Western traditions based on concepts of individual autonomy, informed consent, and truth telling do not fit all cultures and societies. For example, many cultures do not share the primacy of the value of individualism and individual autonomy. 4,5 The family as a whole rather than the individual may make important health care decisions. In addition, truth telling in the setting of advanced disease may be seen as doing harm rather than doing good. The norms of society change, however, and multiple subcultures may be present in one society and indeed in one family.

In some cultures, societies, and religions, moral distinctions (the distinction between good and bad or right or wrong behavior in a moral sense) differ from the dominant culture. The following examples illustrate end-of-life situations viewed through the lens of "Western" bioethics where no moral distinctions are made¹: (1) Withholding versus withdrawing treatment is not morally distinct. A justification for not starting a treatment is also sufficient for stopping it. (2) Artificial nutrition and hydration (ANH) and other life-sustaining technology such as a ventilator are medical treatments, and no morally relevant differences exist



between them. Although there is no moral distinction, they can feel different because of the meaning of food and water throughout life. (3) The right to refuse treatment is not dependent on the type of treatment. A person with capacity has the right to refuse any or all treatment. These are qualityof-life judgments. The Principle of Double Effect (ie, intended versus unintended but foreseeable consequences of an action) is also relevant here. For example, a symptomatic patient at end of life may require increasing doses of sedation and analgesics to control symptoms. Although escalating doses do not hasten death in most patients, it may do so in a specific case. To evoke the Principle of Double Effect, the act must be morally good or neutral (eg, controlling symptoms); the good effect is intended (relieving suffering); the bad effect is merely foreseen as a potential but not intended (hastening death); the bad effect is not the means to the good effect (intent to kill the patient to relieve suffering); and proportionality—the good trying to achieve outweighs the bad that might happen^{3,5} (this may vary based on goals of care). When cultural or spiritual values are in opposition to the dominant culture's norms, ethical conflicts may arise. It may be difficult to know the right thing to do. At best, we try to reach a consensus that is based on sound moral and sensitive ethical reasoning and evidence.²

A brief discussion of the evolution of modern bioethics, examples of federal and state law that support patient autonomy, and various theories of bioethics deliberation will follow. This background will help place the current Western approach to ethical dilemmas within a historical context. In addition, it may also help highlight areas where patients and staff from different cultures and world views can experience difficulties when faced with cultural norms at variance with their own. Preventive and organizational ethics can help through promoting an environment where early identification of these issues and anticipation of possible dilemmas can serve to proactively avert potential areas of conflict. This is done through education, policy development, and case consultation.

THE EVOLUTION OF BIOETHICS AND THE PATIENT AUTONOMY MOVEMENT

The evolution of bioethics and the patient autonomy movement can be traced back to the Nuremberg trials of physicians and researchers, who had subjected concentration camp victims and prisoners in World War II to nonconsensual harmful experimentation. As a result of these trials, the first international code of research ethics—the Nuremberg Code—was created. The code established that patient autonomy and voluntary decision making are integral to human experimentation. Furthermore, the Code stated that human research subjects' participation in studies must be voluntarily and they must be fully informed.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

In the United States, three human research studies involving some of our most vulnerable citizens—the elderly population, the young and mentally handicapped, and incarcerated minorities—resulted in widespread national condemnation and led to the establishment of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The first study involved elderly patients with chronic illness who were injected with live cancer cells in an effort to discover whether the cells would survive in a person who was ill but did not previously have cancer. No consent was obtained from patients or family members.⁵ The second study began in 1932, when the Public Health Service initiated a syphilis study on 399 black men from Tuskegee, Alabama. The goal of the study was to observe the men over a period of time to examine how the disease progressed in individuals of African descent. When the study began, there was no cure for the disease; however, 15 years into the study, penicillin was discovered to be a cure for syphilis. The research participants were never informed, and treatment was withheld despite the fact that by the end of the experiment in 1972, 128 men had died either from the disease or related complications.⁵ The third study, conducted in 1967, involved children with mental retardation at the Willowbrook State School in New York. The children were injected with hepatitis in the hope of finding a way to reduce the damage done by this disease. Although consent was obtained from parents in this study, the consent sometimes had an element of coercion. Gaining admission to the school was difficult and parents were given a guarantee that their child would be admitted if they consented to the participation of their child in the study.

The Belmont Report

In 1979, the National Commission for the Protection of Human Subjects published the Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. Three basic ethical principles were the underpinning of this report: (1) respect for persons (autonomy), (2) beneficence/nonmaleficence, and (3) justice. The commission recommended that all institutions receiving federal research funding establish institutional review boards. These boards, made up of researchers and lay people, were to review biomedical and behavioral research proposals to ensure that these met ethical standards for protecting the rights of the potential subjects. The principles of bioethics were gaining acceptance as a national norm. Today, every medical institution within the United States has a multidisciplinary institutional review board.



TWO LANDMARK CASES THAT BROUGHT BIOETHICS TO THE LEVEL OF THE INDIVIDUAL

These landmark cases transformed physician paternalistic authority into patient autonomy and a model of shared decision making. The two cases, the New Jersey Supreme Court Decision in the Matter of Karen Ann Quinlan⁸ (1976) and the US Supreme Court Decision in the Matter of Nancy Cruzan⁹ (1990), are recognized as being seminal in influencing the medical and legal community. The Karen Ann Quinlan case is significant because it was the first case to deal specifically with the question of withdrawing ventilator support from a permanently unconscious patient. In the Nancy Cruzan case, the issue was the right to discontinue artificial hydration and nutrition (recognized as medical treatments) in a permanently unconscious person. Both cases addressed patient's rights to refuse treatment and the question of who can speak for a person who no longer has the capacity to make medical decisions for himself/herself.

FEDERAL AND STATE LAWS

Federal and state laws have evolved from these early landmark cases that continue to protect the rights of the individual to determine what health care treatment will or will not be accepted.

The Patient Self-determination Act

An example of federal law is the Patient Self-care Determination Act. This piece of legislation was passed in 1990 and encourages Americans to consider what type of care they would want or not want to receive at the end of life. ¹⁰ It gives patients with capacity the right to participate in and direct their own health care decisions, the right to accept or refuse medical or surgical treatment, and the right to appoint someone to make decisions for them if they are no longer able to do so for themselves. It encourages the use of advance directives to this end. The law requires Medicare and Medicaid providers (hospitals, nursing homes, hospice programs, home health agencies, and Health Maintenance Organizations) to give adult patients at time of inpatient admission or enrollment certain information about these rights under the law.

The New York State Health Care Proxy Law

An example of a state law is The New York Health Care Proxy Law, passed in 2011, which allows patients to appoint someone they trust (called a Health Care Agent) to make health care decisions for them if they lose the capacity to do so for themselves. ¹¹ The patient can give the agent/proxy as much power as he/she wants—to make all medical decisions based on his/her communicated wishes or only certain ones. The role of palliative care and hospice nurses is particularly important here as they

are well positioned to enhance the decision-making process by discussing treatment options and the benefits and burdens of each. 12,13 They can address patient's concerns about burdening their families with difficult decisions and can educate the patient and families about the importance of having advance directives so that their wishes and values can be honored. In that way, the family is relieved of some of the burden of decision making as the decisions were made in advance by the patient. It is the patient's decision regarding care, and the family's or surrogate's role is to make sure those decisions are honored. The nurse can encourage the completion of the document and sharing of the information with appropriate parties, including the designated decision maker, physician, and other members of the health care team. If the patient loses capacity to make health care decisions and has not completed a Health Care Proxy Form or designated a health care agent, nurses can be an integral support to the surrogate (see Family Health Care Decision Act) in making sure that the patient's values are honored.

The New York State Family Health Care Act

A second example of state law is the New York State Family Health Care Decision Act, which came into effect in 2010. 14 Other states have similar acts. It establishes the authority of surrogates within a specific hierarchy (court-appointed guardian, spouse or domestic partner, adult child, parent, sibling, close relative, or close friend) to make medical decisions for a patient who has lost decision-making capacity and had not previously appointed a health care agent or left prior instructions regarding care and treatment.

The New York State Palliative Care Act

A final example of a recent state law is The New York State Palliative Care Information Act, which came into effect in 2011. 15 Under this act, physicians and nurse practitioners are required to offer patients with a life expectancy of 6 months or less information and counseling concerning palliative care and end-of-life options. The law is intended to ensure that patients are fully informed of the options available to them when faced with a terminal condition. so they are empowered to make choices consistent with their goals of care, values, and wishes and to optimize their quality of life. The law is not intended to limit treatment options but to encourage open communication and ongoing conversations. Information to be offered includes prognosis, range-of-care options appropriate to the patient, risks and benefits of various options, and the right to comprehensive pain and symptom management at the end of life. If the patient lacks medical decision-making capacity, the information and counseling must be provided to the person who has authority to make health care decisions for the patient. If the attending health care practitioner is not willing to provide the patient with information and



counseling, the law requires that the practitioner arrange for another physician or nurse practitioner to do so or refer or transfer the patient to another physician or nurse practitioner.

These laws, both federal and state, give individuals with capacity the right to participate in and direct their own health care decisions, including the right to accept or refuse medical or surgical treatment and the right to appoint someone to make decisions for them if they are no longer able to do so for themselves. These examples reflect legal support for autonomous decision making by patients. They also underscore the responsibility of providers to provide relevant information to patients and families so that they are fully informed before making these decisions.

POSITION PAPERS FROM PROFESSIONAL NURSING ORGANIZATIONS

In addition to these federal and state laws, the American Nurses Association and the Hospice and Palliative Nurses Association have a variety of position statements related to ethical issues in nursing care, including a code of ethics for nurses with interpretive statements. Other examples include foregoing nutrition and hydration; registered nurses' responsibility in providing expert care and counseling at the end of life; nursing care, do not resuscitate, and allow natural death decisions; euthanasia, assisted suicide, and aid in dying; and withholding and/or withdrawing life-sustaining therapy. Discussions around these issues are not uncommon in palliative care and hospice care, and it is incumbent on the nurse to be familiar with these position statements and how these apply to their practice setting. Many of these topics will be covered in future articles. In addition, the reader is referred to the American Nurses Association and Hospice and Palliative Nurses Association Web sites, where these position statements are readily available.

ETHICAL THEORIES THAT HAVE INFORMED BIOETHICS

Bioethics is a specialized field within ethics as a whole. In Western culture, ethics is an ancient field that has been shaped by more than 20 centuries of discourse among philosophical, cultural, and religious thinkers. A principal thread within this tradition has been to explain our ethical sentiments and judgments. The problem is that we all have ethical feelings and judgments, a great many of which we agree upon; for example, we may all agree that certain forms of behavior are good, but we often find that we cannot clearly or consistently answer the question why they are good. A number of schools of thought have arisen in our history that attempt to give frameworks for answering these kinds of questions, and these have been absorbed into

both our institutions and our everyday thinking. The statements, acts, and laws cited above all use elements of these theories, and we ourselves often call upon them when confronted with ethical questions in our personal or professional lives. Some key principles from these theories are reviewed below so that you may be aware of their underlying influence on bioethics and so that you can attempt to draw on them to help resolve ethical problems that arise in your work within nursing. However, we should all be aware that these are theories from the Western tradition. Other cultures have developed their own discourses and theories about ethical problems, some of which parallel Western thinking, but others of which may not. These arise frequently in our multicultural society, and we must be sensitive to these differences and, ideally, find common ground to the extent we can.

Utilitarianism

Utilitarianism is the theory that actions are good when they maximize overall happiness, not just for the actor but also for others and indeed for the world as a whole. Utilitarianism therefore places a premium on the consequences of action and declares that of two courses of action, the one that creates more overall happiness is the best. Utilitarianism thus broadly accords with our natural sense that good acts are ones that go beyond our personal benefit and benefit the world beyond ourselves. However, it is not always easy to know what generates the most overall benefit, and different schools of thought have arisen within utilitarianism that frame different answers, for example, rule utilitarianism and act utilitarianism. A rule utilitarianism operates on precedent. Once it is established that a general rule serves the greater good, they advocate that such a rule should be adhered to regardless of individual consequences. An act utilitarian is more pragmatic. Rather than setting down broad social rules, this type of utilitarian advocates maximizing of the "good" in each separate situation. For example, a rule utilitarian may advocate that nurses should always be honest with patients. The justification is that honesty in the nursing profession is an important standard and generates patient trust. However, an act utilitarian may not be honest with the patient in a given clinical situation if the beneficial consequences may be maximized by avoiding the truth.^{3,5}

Deontology and Kantian Ethics

Philosopher Immanuel Kant argued that motives rather than consequences are critical to ethical action. Good actions are performed out of a sense of duty regardless of possible consequences, and one's primary duty is to follow universal laws of reason that apply consistently and equally to all people. His famous "categorical imperative" stated that "one should act only on the maxim whereby you can at the same time will that it should become a universal law" and that one must treat yourself and other people as

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ends in themselves, not just as means to an end. This moral test requires that an action be applied to all persons in similar situations. An example of this might be that every patient with advanced cancer is informed of the extent of his/her disease regardless of his/her personal psychological state.^{3,5}

Casuistry

Casuistry reflects case-based reasoning. A casuistry approach to bioethics uses history, past paradigmatic cases, and factual circumstances to determine appropriate decision making. Like legal case law, a casuistry approach considers the specific facts of an ethical dilemma and compares them to past similar ethical cases in order to come to a decision. It favors analogy over deductive reasoning. The rulings in the two landmark cases (Karen Ann Quinlan and Nancy Cruzan) previously discussed and their influence on patient autonomy and the right to refuse treatment are examples.⁵

Virtue Ethics

The theory of virtue ethics is character based. Unlike the other theories previously discussed, virtue ethics emphasizes the pursuit of virtuous characteristics by health care providers. Integrity, fidelity, respect, sympathy, fairness, skill, wisdom, and knowledge are characteristics to be aspired by health care providers that guide appropriate behavior. There are two interlocking frameworks that help determine what character traits are virtuous: the individual and the communal. Virtue ethics only make sense in a moral world in which there are defined purposes or goals for individuals, groups, and activities. To example, the goal of palliative care and those working in palliative care is to reduce suffering and enhance quality of life for patients and their families. These goals suggest desirable character traits and skills necessary for those working in the field.

Principle Theory

The principles of autonomy, beneficence, nonmaleficence, and justice as emphasized in the Belmont Report are the basis of most bioethical deliberations used by clinicians in the West and will be reviewed in most detail. Aspects of the previously discussed general theories are imbedded within it.

Autonomy

The principle of autonomy is based on respect for the individual and can be recognized as influenced by Kantian ethics.³⁻⁵ It proscribes that persons with decision-making capacity should be allowed to make health care decisions for themselves. Patients with capacity may appoint another person to make decisions for them. This is an autonomous decision on their part. Consent cannot express autonomy unless it is informed and without undue influence. Informed consent is a process in which patients with decision-making capacity are provided information about a treatment or

procedure that they may choose to undergo or not to undergo. Patients need to have adequate information to be able to weigh the possible risks, benefits, and consequences of deciding to accept or forgo a treatment, intervention, or procedure. Both the disclosure of information and the active participation of the individual are important to this process. Respecting autonomy involves acknowledging rights and enabling a person to act. Autonomy in health care focuses on informed consent. It is strongly emphasized in the Belmont Principles that special care must be taken to ensure that people without capacity are adequately protected.

Beneficence

The principle of beneficence refers to doing good—providing care that enhances the patient's well-being and reduces risk of harm.³⁻⁵ The Belmont Principles also address research subjects.⁷ Research that can present risks of harm to the subject can still be performed within the principles if the subject has given informed consent. The health care team works together to minimize patient risks and optimize patient benefit. This involves advocating for the patient and family and making sure that their voice is heard.

Nonmaleficence

This is reflected in the Hippocratic oath: "I will use treatment to help the sick according to my ability and judgment but I will never use it to injure or wrong them." Offering nonbeneficial or futile treatment would be an example. This principle asserts a duty to avoid harm and reduce the risk of harm.³⁻⁵ It requires weighing relative risks and benefits of any action or inaction to the patient in front of you. Some treatments may cause a degree of harm, but the benefit to the patient outweighs the harm. For example, chemotherapy may be recommended to reduce tumor size or pain but may cause adverse effects such as nausea and vomiting.

There is sometimes tension between the principles of nonmaleficence and beneficence depending on the lens of the beholder and differing goals and values. For example, an imminently dying patient may ask to be sedated for intractable symptoms as life draws to a close. His goal is to achieve a peaceful death and not to suffer. The health care team supports this request as the only means to relieve the suffering of this dying man (a beneficent act). The family, however, ask that the sedation be withheld as they fear it will hasten the patient's death and will prevent him from interacting with them (maleficence—a harmful act in their eyes). Understanding and mediation are required recognizing that both viewpoints aim at doing "good" and protecting the patient.

Justice

This principle refers to providing care that is equitable and fair to all and includes the fair distribution of scarce resources.³⁻⁵ The availability of palliative care and hospice



care is a good example. All patients should have access to palliative care and hospice care services, interventions, and support; and care provided should be based on patient need regardless of socioeconomic state or social status.

Religious Considerations

Although only briefly touched on here, religious and spiritual considerations play an important role in how patients and their families make decisions at end of life and indeed who are the key decision makers. For example, the rabbi may be the one to whom a Jewish family turns for guidance as to what is or is not permitted regarding withholding or withdrawal of treatment at end of life. The Catholic may turn to the priest and the Muslim to the Imam. The major monotheistic religions—Judaism, Christianity, and Islam have key moral norms that are "absolute rules" from above. In other words, there is a greater authority than that of man, something greater than oneself—a greater power. Other religions such as Buddhism, Hinduism, and Jainism believe in concepts of karma or a cosmic moral order that creates consequences for an action. Religious beliefs and spirituality are integral to the way we approach life and end of life and how we make decisions on the type of care that we want to receive as life draws to a close. 16-18

THE IMPORTANCE OF CONTEXT IN ETHICAL REASONING

Although knowledge of the history of bioethics and bioethics theories is helpful as a foundation for ethical reasoning, bioethics is about stories and suffering. It is hard to balance the ethical principles hypothetically; a context is needed. The case study to follow and the Table will provide steps to analyze and participate in discussions of situations seen as ethically challenging and to explore the context within which these situations have arisen. The role of the nurse will be reflected in both the case and in the discussion.

CASE: A DYING WOMAN WITH ADVANCED DEMENTIA

Mrs S is an 88-year-old widow with advanced dementia being cared for at home by her daughter and home hospice. Her daughter is distressed that her mother is no longer able to eat or drink "enough to sustain life" and asks the hospice nurse if a feeding tube could be inserted so that she could be fed without the stress of attempted oral feeding. The daughter described her mother as a very independent person who had always extended a helping hand to others but rarely asked for help for herself. The Catholic Church was reported as a place of comfort for her. This elderly woman did not have an advanced directive, and she had never indicated verbally what she would want if she was no longer able to eat and drink independently. She had however expressed a dread of being dependent on others. Independence and self-sufficiency were fundamental values to her and were reflected, according to her daughter, in the way she had lived her life.

Ethical Analysis

This was a much-loved and well-supported woman with a daughter who wanted to do what was best for her mother. The ethical questions raised by the hospice nurse were whether the provision of ANH to Mrs S, who no longer had

TABLE Steps to Analyze Situations Seen as Ethically Challenging and to **Explore the Context Within Which** These Situations Have Arisen

- 1. Review the overall situation—identify what is going on in this case.
- 2. Identify the ethical dilemma(s).
- 3. Gather all relevant facts about the patient and the contextual situation, including:
 - a. significant medical and social history,
 - b. involved family,
 - c. decision-making capacity,
 - d. existence of advance directives—written, appointed, or verbal—and any pertinent institutional policies, and
 - e. surrogate or health care agent if decision-making capacity is absent.
- 4. Identify the parties or stakeholders involved in the situation, including those who will be affected by the decision(s) made.
- 5. Identify relevant legal data, including both state and federal laws.
- 6. Identify religious or cultural issues.
- 7. Identify specific conflicts of ethical principles or values. Identify and consider nursing guidelines and the profession's code and position statements.
- 8. Identify possible options, their purpose, and their probable consequences to the welfare of the patient. Identify and make use of interdisciplinary and institutional resources, including ethics committees, social workers, chaplains, and other experienced colleagues.
- 9. Identify practical constraints to decision making, including institutional, legal, organizational, and economic.
- 10. Review and evaluate the situation after action has been taken—debrief and support the staff.

Source: Data from Schwarz and Tarzian.^{3(p130)}

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the capacity to make health care decisions for herself, reflected her previously expressed goals and values and whether any benefits of the intervention (beneficence) are disproportionate to the risks (maleficence).

The nurse used the following points when discussing the situation with the hospice team:

- Mrs S had advanced dementia, which is a terminal disease.
- Mrs S lacked decision-making capacity and had not left an advance directive or appointed a health care agent. She had, however, expressed a dread of dependency on others.
- Her daughter was her surrogate and had the legal authority to make health care decisions for her mother.
- 4. Religion was important to them both, and in the past, they had been guided by their priest when difficult decisions needed to be made.

The team raised the following questions:

- 1. What benefits and burdens is Mrs S likely to incur from AHN (beneficence versus maleficence)?
- 2. Is ANH providing basic care or is it a medical intervention?
- 3. How much weight should Mrs S's goals and values be given, derived from her daughter's narrative of how her mother had lived her life and what was important to her, when advising about the benefit and burden of ANH (autonomy and respect for the person)?
- 4. Are there religious constraints on not providing ANH in this terminally ill woman? (After being apprised of Mrs S's terminal state and specific medical situation, withholding ANH was deemed by the priest as being consistent with Catholic views.)

Following on the team discussion, the hospice nurse, who had a strong relationship with the patient and her daughter, was able to guide the daughter in her role as surrogate decision maker. The daughter decided that ANH would cause more harm than benefit to her mother, that she would continue to offer food by mouth but not force her to eat, and that she would focus on the goal of making her mother as comfortable as possible to ensure that she had a peaceful death.

SUMMARY

Ethical issues at end of life are not primarily medical or science issues but social, legal, religious, and cultural. As societies become increasingly diverse and multicultural, values and norms of behavior may differ. This can give rise to conflict and ethical dilemmas. Nurses working within a

specific dominant culture and tradition need to respect the dominant tradition of the institution where they practice at the same time negotiating between ethical systems to meet the goals of the patient.

References

- Hospice Foundation of America. Ethics—A Case Study Approach. Part of the Living With Grief Series. Doka KJ, Tucci AS, Corr AA, Jennings B, eds. Washington, DC: Hospice Foundation of America; 2012.
- 2. Wiegand D, Russo MM. Ethical considerations. In: Dahlin CM, Lynch MT, eds. *Core Curriculum for the Advanced Practice Nurse*. 2nd ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2013;39-59.
- Schwarz JK, Tarzian AJ. Ethical aspects of palliative care. In: Matzo M, Witt Sherman D, eds. *Palliative Care Nursing: Quality Care to the* End of Life. New York, NY: Springer Publishing Company; 2010: 119-141.
- Prince-Paul M, Daly BJ. Ethical considerations in palliative care.
 In: Ferrell BF, Coyle N, eds. Oxford Textbook of Palliative Nursing. Oxford: Oxford University Press; 2010:1157-1175.
- 5. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 6th ed. New York, NY: Oxford University Press; 2008.
- 6. Krugman S. The Willowbrook Hepatitis Studies revisited: ethical aspects. *Rev Infect Dis.* 1986;8:157-62.
- 7. The Belmont Report. DHEW Publication No. (OS) 78-0013 and No. (OS) 78-0014 (1979).
- 8. In re Quinlan, 775 A2A 647 (NJ), cert denied, 429 70 NJ 10, 355 A2d 647 (1976).
- 9. Cruzan v Director. Missouri Department of Health, 497 US 261, 110 S Ct 2841 (1990).
- 10. Patient Self-determination Act 4206-4751. Pub L No. 101-508.
- New York State Department of Health. Health care proxy. http:// www.health.ny.gov/forms/doh-1430.pdf. Accessed October 25, 2013
- Peereboom K, Coyle N. Facilitating goals of care discussions for patients with life-limiting disease—communication strategies for nurses. J Hosp Palliat Nurs. 2012;14:251-258.
- Dahlin CM. Communication in palliative care: an essential competency for nurses. In: Ferrell BF, Coyle N, eds. Oxford Textbook of Palliative Nursing. Oxford: Oxford University Press; 2010; 107-133.
- New York State Bar Association. Family Healthcare Decisions Act information center. http://www.nysba.org/FHCDA/. Accessed October 25, 2013.
- 15. New York State Department of Health. http://www.health.ny.gov/professionals/patients/patients_rights/palliative_care/information. Accessed October 25, 2013.
- Taylor EJ. Spiritual assessment. In: Ferrell BF, Coyle N, eds. Oxford Textbook of Palliative Nursing. Oxford: Oxford University Press; 2010:647-661.
- McClement SE, Chochinov HM. Spiritual issues in palliative medicine. In: Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK, eds. Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press; 2010:1403-1409.
- 18. Neuhaus RJ, ed. *The Eternal Pity—Reflections on Dying*. Notre Dame, IN: University of Notre Dame; 2000.

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