Topic 15: *Ethical Issues of Elder Care*

Competencies

1. Apply the concept of decision-specific capacity to older adults.
2. Apply legal and ethical principles in the analysis of complex issues related to care of older adults: informed consent, refusal of treatment, and advance directives.
3. Define ethics, bioethics, ethical dilemma, and nursing ethics.
4. Describe the major ethical principles that have an impact on older adults' health care.
5. Discuss the difference between personal values and professional codes of ethics.
6. Apply a decision-making model to an ethical dilemma in nursing practice.

Topic 15: *Ethical Issues of Elder Care*

Content Outline

1. **Apply the concept of decision-specific capacity to older adults.**

   A. *Decision-making capacity* is a clinical determination as to whether a person possesses a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate about choices.

   B. *Competency* is a legal determination (by a judge) as to mental disability or incapacity; whether a person is legally fit and qualified to give testimony or execute legal documents. The law presumes that all adults are competent and have the decision-making capacity to make health decisions. To be considered competent, an individual must be able to comprehend the nature of the particular action in question and be able to understand its significance.

   C. Because a substantial number of older adults have altered decision-making capacity, the following should be kept in mind:
      - Decisional capacity is an issue every time an older person is asked to consent to treatment, to participate in a research study, or to execute a Health Care Proxy (HCP), and/or Living Will.
      - As long as a person retains decision-making capacity, his or her wishes and decisions govern health care.
      - A person's capacity to make health-care decisions is usually self-evident. On the other hand, in advanced old age and in the face of dementia, it is often unclear

as to whether a person is capable of making specific health-care decisions for themselves.

- Rather than construing capacity as being either totally present or absent, the literature endorses the concept of *decision-specific capacity.* Decision-specific capacity depends on a person's ability to make a specific decision in question. In the old construct of global decisional capacity, capacity was either present or absent; an "on/off" switch. In this newer construct of decision-specific capacity, capacity is not an absolute, it is a "dimmer" switch.
- Cognitive impairment does not automatically constitute incapacity. Most older adults with impaired, fluctuating, or questionable cognitive status, including those with mild and moderate dementia, retain sufficient cognitive capability to make some, but not necessarily all, health-care decisions. For example, an older person may lack the decision-making capacity to consent to a feeding tube while retaining the capacity to appoint a child to make decisions for them.
- There is no "gold standard" for capacity determination.
- Widely used tests of mental status assessment (e.g., Mini-Mental Status Assessment or MMSE) are not definitive measures of an individual's ability to make specific health-care decisions.

D. *Verification of decision-making capacity* is required when a person is refusing or giving consent for treatment and/or executing an advance directive. Verification

follows an informed consent model and typically encompasses the following steps:

1. *Ability to voice a choice or preference:* Because health-care decisions require that a person choose or select among different options, ability to choose is a prerequisite to making health-care decisions. When a person's ability to choose is in doubt, as may be the case with older people with dementia, it can be verified by asking simple questions such as: "Which do you prefer, blue or red?" "Which do you prefer, television or radio?" "Which is your favorite season, summer or winter?" "Which meal do you like best, breakfast or lunch?" (*Note:* Ability to choose is decision-specific rather than a measure of global capacity.)

2. *Adequate disclosure:* Information about the diagnosis, nature, and purpose of the proposed treatment, risks, and consequences, probability of a successful outcome, benefits and risks, and prognosis if treatment is not instituted must be provided in such a way that a person can fully appreciate the information. For an older person, adequate disclosure is dependent on attention to appropriate use of eye glasses, hearing aids, and written materials, consideration of time of day, and complexity of rapidity with which information is given.

3. *Comprehension (understanding) of information:* Decision making is predicated on understanding or

grasping specific information. Understanding can be verified by:

a. Recall of information: Asking a person to tell you in his or her own words the specific information he or she has been given about a treatment or advance directive, or asking a person to differentiate a correct statement from an incorrect statement in relation to the information that was presented, similar to a true/false question.

b. Manipulating information: Asking a person to manipulate the information he or she has been given. For example, a person signing for an amputation should be able to state the functional impairments he or she will have as a consequence of the loss of a limb. Older people may need more time to demonstrate they can adequately manipulate information.

c. Appreciation of the situation: Asking people to contemplate the consequences of what will happen should they choose not to agree/or to agree to the treatment. For example, a person who chooses not to execute a health-care proxy should be able to say that he or she knows this will limit family member's ability to act on their behalf should they lose decision-making capacity.

4. *Voluntary consent:* A person must not be persuaded or coerced in any way to accept a treatment or undergo a

procedure. The voluntary nature of consent is jeopardized if an older person feels compelled to comply with physician or family expectations, or fails to fully appreciate possible alternatives or consequences.

5. *Consistency:* A decision is thought to be valid when it reflects a person's "true or authentic self." A person's choice of the same decision over a period of hours, days, and weeks provides evidence that the decision truly reflects the person's preference.

2. Apply legal and ethical principles in the analysis of complex issues related to care of older adults: informed consent, refusal of treatment, and advance directives.

A. *Informed consent:* A legal doctrine requiring the disclosure of information about a proposed treatment before obtaining consent for its performance. Informed consent involves providing factual information, including the benefits and burdens of an action, and determining a person's understanding of that information. After being given information, a person is thought to be able to give informed consent if they: (a) can make a choice, (b) understand and appreciate the issues, (c) rationally manipulate information, and (d) make a stable and coherent decision.

The following age-related changes influence or may impede the process of informed consent for older adults:

1. Sensory deficits in hearing and vision.
2. Impaired ability to ask a question.

3. Both written and verbal information must be presented appropriately with opportunities to repeat and clarify content.
4. Values and beliefs about making health-care choices (i.e., "let the doctor decide").
5. Decision-making capacity that fluctuates or is diminished.

B. *Refusal of treatment:* As at any age, older people with decision-making capacity have the right to refuse treatment, even if such refusal hastens or results in their death. Determining whether the older person has the requisite capacity to refuse a particular treatment follows the process described in A.

1. As for all people, it is ethically and legally permissible for an older person or their proxy (see below) to elect to try a treatment—for example, a respirator—and then to decide to discontinue it. This may occur more frequently with older people where the potential benefits of a treatment may be less clear than with younger adults.
2. Ethically and legally there is no difference between never starting a therapy (such as tube feeding) and discontinuing therapy.

C. *Advance directives:* Advance directives allow individuals to exercise control over their bodies and direct their health care in the event they will lack decision-making capacity at the time a medical decision needs to be

made. Older people are more likely to develop impaired decision-making capacity than are younger people. Thus, advance directives are very important documents for older adults.

The two most commonly used advance directives are Living Wills and Durable Powers of Attorney for Health Care (Health-Care Proxy).

A living will provides specific instructions about the particular kinds of treatments/interventions an individual would or would not want to prolong or sustain life. Living wills are generally used to declare wishes, to refuse, limit, or to withhold life sustaining treatment under certain circumstances should the individual lose capacity and become unable to communicate.

A health-care proxy (HCP) permits an individual to designate another person who is presumably known and trusted by the patient to make health-care decisions for them should they lose decision-making capacity. The agent or surrogate can interpret the individual's wishes as medical circumstances change.

Among the general public, between 15% and 25% of people have either a living will or health-care proxy. Of patients with dementia, 14% are thought to have a HCP or living will. In nursing homes, where between 44% and 70% of residents have dementia, 20% to 90% of residents have advance directives; approximately 50% have Do Not Resuscitate (DNR) orders.

D. *The Patient Self-Determination Act:* Enacted by Congress in 1991, this federal law, the Patient Self-Determination Act (PSDA), creates obligations for health-care facilities participating in the Medicaid and Medicare program to: (1) Ask patients whether they have an advance directive and to record this information in the medical record; (2) to honor advance directives; (3) to educate patients about advance directives; (4) to conduct community education; and (5) to provide care and not discriminate against a patient whether or not the patient has executed an advance directive.

3. Define ethics, bioethics, ethical dilemma, and nursing ethics.

A. *Ethics* are declarations of what is right or wrong and what ought to be. Ethics is a specialized area of philosophy with origins dating back to ancient Greece. The ethical principles enunciated by Hypocrates still serve as the underpinings of many of today's ethical issues in medicine. Ethics has its own language and terminology that are used in very precise ways.

B. *Bioethics* is defined as the application of ethics to matters of life and death. Bioethics implies that a judgment should be made about the rightness or wrongness, goodness or badness, of a given medical or scientific practice. Nurses are concerned about both bioethics and ethics.

C. *An ethical dilemma* can be defined as (1) a difficult problem seemingly incapable of a satisfactory solution; or (2) a situation involving a choice between two equally unsatisfactory alternatives. This is not to suggest that all dilemmas in life are ethical in nature; rather, that ethical dilemmas arise when moral claims conflict with each other.

D. *Nursing ethics* refers to the application of ethical principles in nursing practice.

4. Describe the major ethical principles that have an impact on older adults' health care.

There are seven key principles that underlie ethical dilemmas: autonomy, justice, beneficence, nonmaleficence, veracity, best interest standard, and substituted judgment standard.

A. *Autonomy* is the right to self-determination, independence, and freedom. Autonomy in the health-care setting involves the health-care provider's willingness to respect a patient's right to make decisions about and for himself, even if the provider does not agree with the patient's decisions. Nurses may interfere only when they believe a person does not have sufficient information or capacity to understand, or is being coerced. Nurses have no duty to assist people to carry out damaging decisions, nor do they have a duty to assist people to harm themselves. The principle of informed consent is embedded in autonomy.

B. *Justice* is the obligation to be fair to all people. Individuals have the right to be treated equally regardless of race, sex, marital status, medical diagnosis, social standing, economic level, or religious belief. The notion of justice is sometimes expanded to include equal access to health care for all. As with other rights, limits can be placed on justice when it interferes with the rights of others.

C. *Beneficence* is the "doing good" theory. It requires that health-care providers do good for patients under their care. Good care requires that the health-care provider understand the patient from a holistic perspective that includes the patient's beliefs, feelings, and wishes as well as those of the patient's family and significant others.

   Beneficence dictates more than technical competence; it involves acting in ways that demonstrate caring: listening, empathizing, supporting, nurturing, and advocating. Beneficence is the motivating force behind caring; however, beneficence is complex because it is difficult to determine what exactly is good for another and who can make the decisions about what is good.

D. *Nonmaleficence* is the requirement that health-care providers do no harm to their patients. It is the opposite of beneficence. The principle of nonmaleficence also requires that health-care providers protect those individuals from harm if they cannot protect themselves. This protection is particularly evident in children and older adults as seen in abuse laws.

E. *Veracity* or truthfulness requires that health-care providers not intentionally deceive or mislead patients. The principle is based on mutual trust and respect for human dignity. Without honesty, meaningful relationships break down. As with the other rights and obligations, there are limitations to this principle; for example, where telling patients the truth would seriously harm or would produce greater illness or goes against the cultural mores of the patient. Nonetheless, feeling uncomfortable delivering bad news is not, in and of itself, an acceptable reason for being untruthful.

F. *Substituted judgment standard* is a decision made for an individual when the surrogate decision maker knows what the person would want and would actually do if they were able to communicate their wishes.

G. *Best interest standard* is a decision made about an individual patient's health care when the patient is unable to make an informed decision for her own care. This standard is based on what health-care providers and/or families decide is best for that individual. It is very important to consider the individual's expressed wishes, either formally in a written declaration or informally in what may have been said to a family member.

5. Discuss the difference between personal values and professional codes of ethics.

A. *Personal values:* Most people derive their values from society. A person may internalize some or all of these, perceiving them as personal values. Nurses need to know

what values patients hold about life, family, health, illness, and death. Nursing students should explore their own values and beliefs regarding:

Individual's right to make decisions for self
Euthanasia (active and passive)
Blood transfusions
AIDS/HIV
Withholding fluids and nutrition
Cultural perspectives on life, health, death, etc.
Spiritual/religious beliefs regarding death, etc.

To the extent that nurses hold views in these areas that may make them unable to care for patients with different beliefs, nurses should recognize such differences. In such situations, a number of strategies may be important to enable care provision to continue including (Lo, 1995):

- Acknowledge that a problem exists.
- Understand the patient's perspective.
- Understand your own responses.
- Negotiate mutually acceptable grounds for continued care.

Nurses should identify supports in the community and within their institution that will enable patients to obtain the highest level of care, including, if necessary, options for transferring patients to other health-care providers if a nurse is unable to provide appropriate care while taking into account legal and ethical requirements that patients not be abandoned.

B. *Professional values* are often a reflection and expansion of personal values. They are acquired during socialization into the nursing profession via the code of ethics, standards of practice, nursing experiences, teachers, and peers.

C. *A code of ethics* is a formal statement that sets standards of ethical behavior for a group of people. It is a set of ethical principles that is shared by members of the group, reflects their moral judgments over time, and serves as a standard for their professional actions. It is not a static document. Rather, it is a document of statements of values reflecting social and professional change. The ANA code of ethics for nurses emphasizes the principle of respect for the life and dignity of patients.

6. Apply a decision-making model to an ethical dilemma in nursing practice.

Nurses must understand the basis on which they make their decisions. Ethical reasoning is the process of thinking through what one ought to do in an orderly, systematic manner to provide justification of actions based on principles. Ethical decisions cannot be made in a scattered, disorganized way based entirely on intuition or emotions. Ethical decision making is a rational way of making decisions in nursing practice. It is used in situations where the correct decision is unclear or in which there are conflicts

between rights and duties. A six-step process (Aiken, 1994) for ethical decision making is:

1. Collect, analyze, and interpret the data.
2. State the dilemma.
3. Consider the choices of action.
4. Analyze the advantages and disadvantages of each course of action.
5. Make the decision.
6. Evaluate the effectiveness of the decision.

Aiken, T. (1994). *Legal, Ethical, and Political Issues in Nursing.* Philadelphia: F. A. Davis Co.

Case Study

Mr. L, age 71, had been a patient in the hospital for three weeks after suffering a very severe stroke. He has a tracheostomy (not ventilator dependent) and rarely leaves his bed. He has several infections that respond well to therapy. He communicates by whispering and writing. Many staff members observe that Mr. L seems depressed. He has never been treated for clinical depression. His spouse of nearly 50 years, Mrs. L, visits him faithfully during his hospitalization. She feeds him his lunch and dinner by spoon. She is a much admired visitor and often brings gifts for the staff. She is a "lovely woman, truly devoted to her husband," in the words of the staff social worker.

Mr. L was offered an opportunity to complete an advance directive. He chose to fill out only a Durable Power of Attorney for Health Care (Health-Care Proxy). He named his wife as his surrogate decision maker should he lose decisional capacity. Mr. L's Health Care Proxy was filed in his chart. In a subsequent discussion with his physician, he requested that no cardiopulmonary resuscitation be attempted were he to suffer an arrest. The Do Not Resuscitate order was also appropriately charted.

Later, however, Mr. L told his primary nurse that "when the time comes, I don't want a feeding tube. I would rather starve to death." The nurse reported this statement to the physician. The physician brought up the matter the next day with both Mr. L and his wife. This time Mr. L said nothing. His wife stated, "Well, you know, his mind wanders sometimes. I know that he would not want to die without food or water." Later, outside of the patient's room, Mrs. L told the nurse and doctor, "I don't really care what he says. He doesn't know what he wants. I could never let him die that way. We would both go straight to hell. If he does have another stroke, I will become the decision maker. So it really doesn't matter anyhow."

Evaluation Strategies

1. What are some ethical issues introduced in this case study?
2. Who could be involved in assisting in this situation?
3. How would you plan care for Mr. L based on the information outlined here?
4. What are any thoughts/feelings that you have about this care situation?

A. Apply the ethical analysis framework used for Mr. L to the following case:

An 80-year-old woman is in a persistent vegetative state as a result of a CVA. She has always talked about "someday" signing a living will requesting that heroic measures not be taken but her family wants "everything to be done that can be done." Whose wishes should prevail? Can her undocumented statements be legally honored?

B. True/False

True 1. Ethics and law are guides for resolving conflict between people

True 2. Veracity is the basis for informed consent and the Patient Self Determination Act

False 3. A Durable Power of Attorney for Health Care names a surrogate to make treatment decisions for a capacitated person

C. Multiple Choice

1. When an ethical situation arises where there is a choice between two equally unfavorable alternatives, it is called a(an)
   a. Tort
   b. Ethical antagonism
   c. Contradiction
   * d. Ethical dilemma
2. Autonomy is the belief that people have the right to
   a. Privacy
   b. Confidentiality
   * c. Self-determination
   d. Truthfulness

Evaluation Strategies

3. Beneficence is the expectation that nurses will
   * a. Act in the patient's best interests
   b. Allow patient choices
   c. Be truthful to patients
   d. Uphold patient trust
4. The first step in the ethical decision-making process is to
   a. Consider the alternatives
   * b. Collect, analyze, and interpret the data
   c. Consider the consequences of the actions
   d. Make a decision

Resources

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Other Resources

American Hospice Foundation; Washington, DC
Telephone: 202-223-0204 E-mail: ahf@msn.com
www.americanhospice.org

American Nurses Association (ANA); Washington, DC
Telephone: 202-651-7000; 800-274-4ANA
www.ana.org

The American Society of Bioethics and Hamanities; Glenview, IL
Telephone: 847-375-4745
www.asbh.org

Choice In Dying/Partnership for Caring, Inc.; New York, NY
Telephone: 212-870-2003

National Office; Washington, DC
Telephone: 202-338-9790; 800-989-WILL
www.partnershipforcaring.org

The Hastings Center for Bioethics; Garrison, NY
Telephone: 914-424-4040
www.thehastingscenter.org

Hospice and Palliative Nurses Association; Pittsburgh, PA
Telephone: 412-361-2470
www.hpna.org

American Academy of Hospice and Palliative Medicine; Glenview, IL
Telephone: 847-375-4712
www.aahpm.org

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Resources

The Kennedy Institute of Ethics; Washington, DC
Telephone: 202-687-8099; E-mail: kicourse@gunet.georgetown.edu
www.georgetown.edu/research/kie

The American Society of Law, Medicine and Ethics; Boston, MA
Telephone: 617-262-4990
www.aslme.org

Project on Death in America
www.soros.org/death

The Center to Advance Palliative Care
www.capcmssm.org

National Hospice and Palliative Care Organization (NHPCO)
www.nhpco.org

Hospice Foundation of America
www.hospicefoundation.org
www.growthhouse.org

National Bioethics Advisory Comission (NBAC)
www.bioethics.gov

National Reference Center for Bioethics Literature
www.georgetown.edu/research/nrcbl

Professional misconduct information for nursing, medicine, dentistry, pharmacy, and physical therapy
www.op.nysed.gov/profhome.htm

Professional misconduct and physician discipline information
www.health.state.ny.us/nysdoh/opmc/main.htm

New York State Task force on Life and the Law
www.health.state.ny.us/nysdoh/taskfce/index.htm

American Bar Association Commission on Legal Problems of the Elderly (CLPE)
www.abanet.org/elderly