

Topic 6: Ethics and Teams¹

Overview

Clinicians of different disciplines have always worked together to provide patient care and ensure positive patient outcomes. The process of care was assumed to be smooth and well coordinated. However, beginning with the studies of Knaus et al in the intensive care unit, physicians have increasingly come to recognize the implications of poor communication between physicians and nurses in acute-care settings and by implication in other settings². Knaus demonstrated that poor communication resulted in increased mortality. During the last decade, there has been a growth in community-based care and a concomitant increase in the growth of teams. Interdisciplinary teams are becoming common in the primary care management of complex and chronic conditions such as HIV+ illness, cardiac, and cancer care, major organ transplantation, and end-stage renal disease for patients who are on chronic dialysis. Health care teams may be exceptionally valuable in the management of patients with complex medical and social needs; the different viewpoints can help to ensure that the multifaceted nature of the patient's needs are evaluated and the team can establish their priorities among the recommended solutions to the problems. Most importantly, the team can hear the patient's wishes from multiple perspectives and can clarify the patient and family concerns.

The value of the interdisciplinary primary care team also comes with a price. The addition of non-physician professionals in individual health care decision-making may make it increasingly difficult for patients and families to have their voices heard. Increasingly complex and competitive health care systems make open communication among providers and different health care systems difficult. The team may inhibit discussion of complex ethical dilemmas because providers are managing multiple roles on the team, maintaining their ethical responsibility to the patient, and balancing their legal and financial responsibilities to organizations. Complicating the issue is the discomfort among providers from different disciplines in discussing ethical issues in a group where power, education, and access to the patient are uneven.

The move to home and community-based care creates additional ethical dilemmas about how to maintain patient and family privacy in the face of intrusions by multiple professionals. As teams take an increasingly active role in management of care for patients with complex medical and social problems, they will be more likely to encounter increasing difficulty in processing ethical issues in the management of these patients. Finally, the addition of multiple professionals with differing professional values and clinical expertise only serves to make more complex the mediation of bioethical disputes. Many programs in geriatrics are teaching students the basic theories and methods of ethical analysis. Yet, despite dramatic increases in the volume of primary team care, bioethics training generally examines resolution of ethical dilemmas in terms of a single provider and patient or a group of independent providers interacting around the care of a particular patient, rather than within the context of a health care team caring for clinically complex patients. But in the team environment, students also need an understanding of specific

¹ Topic 6 is from Cassel, C., Mezey, M.D., Bottrell, M.M., Hyer, K., & Howe, J. (Eds.). An ethics casebook in geriatric interdisciplinary team training. Baltimore, MD: The Johns Hopkins Press; in press.

² Knaus, W.A., Draper, E.A., Wagner, D.P., & Zimmerman, J.E. (1986). An evaluation of outcome from intensive care in major medical centers. *Annals of Internal Medicine*. 1986; 104(3): 410-8.

bioethical dilemmas in the management of complex geriatric clients within the context of decision-making by health care teams in their roles interacting with patients, as professionals representing their disciplines, as members of well-established teams, and as representatives of their organization or institution. The curriculum content and tools suggested here are designed to provide ethical theory as well as real-world examples of situations professionals are likely to encounter once they begin caring for patients with complex needs.

Objectives

- Define the terms ethics, ethical dilemma, bioethics, clinical ethics, medical ethics, and nursing ethics.
- Describe the major considerations that should be considered in analysis of ethical dilemmas in health care.
- Apply legal and ethical principles in the analysis of complex issues related to care of the elderly, such as informed consent, and refusal of treatment, advance directives, Patient Self-Determination Act, and just allocation of resources.
- Apply the concept of decision-specific capacity to older people.
- Discuss the difference between personal values, professional values, and professional codes of ethics.
- Apply a decision-making model to an ethical dilemma in clinical practice.

Definition of Basic Terms

Students should understand and be able to define the terms ethics, ethical dilemma, bioethics, clinical ethics, medical ethics, and nursing ethics.

Ethics is defined as 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 Hypocrites still serve as the foundation of many of today's ethical issues. Ethics has its own language and terminology that are used in very precise ways.

An Ethical Dilemma can be defined as 1) a difficult problem seemingly incapable of a satisfactory solution, or 2) a situation involving choice between 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.

The terms bioethics, biomedical ethics, clinical ethics, medical ethics, and nursing ethics are often used interchangeably, the following definitions represent the most common distinctions made in the field.

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.

Clinical Ethics – Clinical ethics is an interdisciplinary activity to identify, analyze, and resolve ethical problems that arise in the care of particular patients. The major thrust of clinical ethics is to work for outcomes that best serve the interests and welfare of patients and their families.

Medical Ethics – A branch of bioethics, medical ethics is generally aimed at examining the moral obligations of physicians in patient care, organizational management, and health policy.

Nursing Ethics – A branch of bioethics, nursing ethics is generally aimed at examining the moral obligations of nurses in patient care, organizational management, and health policy.

Considerations for Ethical Analysis

There are a variety of major considerations that should be considered in the analysis of ethical dilemmas in health care.³ Generally, seven key principles and concepts can be used to analyze ethical dilemmas in health care: autonomy, justice, beneficence, nonmaleficence, veracity, best interest standard, and substituted judgment standard.

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 patients' rights to make decisions about and for them, even if the provider does not agree with the patient's decisions. Clinicians may interfere only when they believe a person does not have sufficient information or capacity to understand, or is being coerced. Clinicians have no duty to assist people to carry out damaging decisions, nor do they have a duty to assist people to harm themselves.

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 upon justice when it interferes with the rights of others.

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 providers 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, and nurturing. 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.

Nonmaleficence is the requirement that health care providers do no harm to their patients. It is the opposite of beneficence and it is difficult to speak of one term without mentioning the other. The principle of nonmaleficence also requires that health care providers protect from harm individuals who cannot protect themselves. This duty to protect from harm is particularly evident for such groups as children and the elderly, as seen in abuse laws.

Veracity, or truthfulness, requires that health care providers tell the truth and 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, in situations 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.

³Beauchamp, T. L., & Childress, J. F. (1994). Principles of biomedical ethics (4th ed.). New York: Oxford University Press. 1994.

Substituted Judgement 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

Best Interest Standard “Best Interest” is a decision made about an individual patient’s health care when the patient is unable to make an informed decision about their own care. This standard is based upon 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.

Key Legal and Ethical Principles

Students should recognize and understand how to apply legal and ethical principles in the analysis of complex issues related to care of the elderly, such as informed consent, and refusal of treatment, advance directives, Patient Self-Determination Act, and just allocation of resources.³

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 can: a) evidence a choice; b) understand and appreciate the issues; c) rationally manipulate information; and d) make a stable and coherent decision.

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

1. Sensory deficits in hearing and vision.
2. Adult learning needs for both written and verbal information presented slowly with opportunities to repeat and clarify content.
3. Values and beliefs about making health care choices (i.e., “let the doctor decide”).
4. Decision-making capacity that fluctuates or is diminished (see below).

Refusal of Treatment:

As at any age, older people with decision-making capacity have the right to refuse treatment, even when doing so acting might cause their death. Determining whether the older person has the requisite capacity to refuse a particular treatment follows the process described later in the text.

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 that treatment. This may arise more frequently with older people when the potential benefits of a treatment are unclear.
2. Ethically and legally there is no difference between starting therapy and discontinuing therapy.

Advance Directives:

Advance directives allow individuals to exercise control over their bodies and direct the health care they want or do not want in the event they will lack decision-making capacity at the time a medical decision needs to be made. Older people are more likely than are younger people to develop impaired decision-making capacity. The two most commonly used advance directives are living wills (LW) and Durable Powers of Attorney for Health Care (health care proxy [HCP]).

A living will provides specific instructions about the particular kinds of treatments/interventions individuals 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.

An HCP permits an individual to designate another person who is presumably known and trusted by the patient to make health care decisions should that patient lose decision-making capacity. The agent or surrogate can interpret the individual's wishes as the medical circumstance changes.

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%-90% of residents have advance directives; approximately 50% have Do Not Resuscitate (DNR) orders.

Patient Self-Determination Act.

Enacted by Congress in 1991, the Federal 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, and 4) to conduct community education.

Just Allocation of Resources:

In health care settings, "justice" usually refers to the just allocation of health care resources. Allocation decisions are unavoidable because resources are limited and could be spent on other social goods like education instead of health care.⁴

Ideally, allocation decisions should be made as part of public policy set by government officials or judges, according to appropriate procedures. Clinicians should participate in public debates about allocation and help set policies. While triage is a common aspect of clinical decision-making, in general, rationing medical care at the bedside should be avoided because it may be inconsistent, discriminatory, and ineffective.

At the bedside, clinicians usually should act as patient advocates within the constraints set by society and sound practice. In some cases, more than one patient may compete for the same limited resources such as the clinician's time or a bed in intensive care. When this occurs, clinicians should ration their time and resources according to patients' medical needs and the probability of benefit.

⁴ Lo, Bernard. (1995). Resolving ethical dilemmas: a guide for clinicians. Philadelphia, PA: Lippincott Williams & Wilkins.

Decision Specific Capacity ⁵

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 their choices.

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 (in the law with regard to health care decisions, there is no definitive test for competency).

Because a substantial number of older people have altered decision-making capacity, the following aspects of decision-making capacity should be kept in mind.

1. 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 living will.
2. As long as a person retains decision-making capacity and full capacity, it is *presumed unless demonstrated otherwise*, their wishes and decisions govern.
3. Usually, a person's capacity to make health care decisions is 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.
4. Rather than being either present or absent, the literature endorses the concept of "decision-specific capacity." ⁶ Decision-specific capacity depends on a person's ability to make a *specific* treatment decision.

Old construct of decision (global) capacity: capacity as either present or absent; an "on/off" switch.

New construct of decision specific capacity: capacity as decision specific: a "dimmer" switch.

5. Cognitive impairment does not automatically constitute incapacity. Older people 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 the daughter to make decisions for them.
6. There is no "gold standard" for capacity determination.

⁵ Strumpf, N., & Shelkey, M. (1999). Physical restraint reduction for older adults. In C. Mariano, New York: John A. Hartford Foundation, Inc.

⁶ Mezey, M., Teresi, J., Ramsey, G., Mitty, E., &M.; Teresi, J.; Ramsey, G.; Mitty, E., &and Bobrowitz, T. (2000). (NYU Division of Nursing, New York 10003, USA). Decision-making capacity to execute a health care proxy: development and testing of guidelines. *Journal of the American Geriatrics Society*,48(2):179-87.

7. Widely used tests of mental status assessment (e.g., Mini-Mental Status Assessment or MMSE) are not good measures of an individual's ability to make health care decisions.

Personal Values, Professional Values, and Codes of Ethics⁵

Faculty should consider using the Values History form and/or the Care Rescue Briefing in conjunction with a discussion of personal values, professional values, and professional codes of ethics to encourage students to examine their own values and the implications of those values for patient care.

Personal Values: Most people derive their values from the society or subgroup of society in which they live. A person may internalize some or all of these values and perceive them as personal values. Clinicians need to know what values they hold about life, health, illness, and death. Specific clinical circumstances and beliefs of patients may be contradictory to the clinician's values. Clinicians should explore their own values and beliefs regarding (including but not limited to):

The individual's right to make decisions for self

- Euthanasia (active and passive)
- Blood transfusions
- AIDS/HIV Disease
- Withholding fluids and nutrition
- Cultural differences
- Spiritual/religious differences

To the extent that clinicians hold views in these areas that may make them unable to care for patients with different beliefs, clinicians should recognize such differences. In such situations, a number of strategies may be important to enable care provision to continue, including:⁴

1. Acknowledge that a problem exists.
2. Try to understand the patient's perspective.
3. Try to understand your own responses.
4. Try to negotiate mutually acceptable grounds for continued care.

Clinicians 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 clinician is unable to provide appropriate care while taking into account legal and ethical requirements that patients not be abandoned.

Professional Values are often a reflection and expansion of personal values. They are acquired during socialization into nursing and may come from codes of ethics, clinical experiences, educational training, teachers, and peers.

A Code of Ethics is a formal statement that set 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 value re-election, social, and professional change.

The American College of Physicians-American Society of Internal Medicine (ACP-ASIM) drafted a set of ethical guidelines relevant to team and system characteristics of caregiving. The Preamble states, "The purpose of this statement of ethical principles is to heighten awareness of the need for principles to guide all who are involved in the delivery of health care. The principles offered here focus health care delivery systems on the service of individuals and the good of society as a whole and can offer a foundation for new and enhanced levels of cooperation among all involved."⁷

The Values History Form, developed at the Center for Health Law and Ethics, University of New Mexico School of Law, recognizes that medical decisions are based on those beliefs, preferences, and values that matter most to us. A discussion of these and other values can provide important information for those who might in the future have to make medical decisions for that individual, when he or she is no longer able to do so. The Values History Form is not a legal document, although it may be used to supplement a Living Will or Durable Power of Attorney for Health Care.

An Ethical Decision-Making Model⁴

Clinicians 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, unorganized approach based entirely on intuition or emotions. Ethical decision-making is a rational way of making decisions in nursing practice. It is used in situations in which the right decision is not clear or in which there are conflicts of rights and duties A five-step process for ethical decision-making follows:

A five step process for ethical decision making:

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

Aspects to consider in each step:

1. Collect, analyze, and interpret the data.

A. Medical facts.

- What is the current medical status?
- Are there other contributing medical diagnoses?
- What is the diagnosis? The prognosis? How reliable are these?
- Has a second opinion been obtained? Would it be helpful?

⁷ Berwick, D., Hiatt, H., Janeway, P., & Smith, R. (1997). An ethical code for everybody in health care. *British Medical Journal*, 315:1633-4. (The authors cite the American Medical Association, the American Hospital Association, and the American Nurses' Association's Code for Nurses with Interpretive Statements.)

- What treatments are possible?
- What is the probable life expectancy and what will be the general condition if the treatment is given?
- What are the risks and side effects of the treatment?
- What is the probability the treatment will be of benefit?
- What benefits will the treatment provide?

2. *Patient preferences.*

- Does the patient have decision-making capacity? Does he/she understand the need for medical care, the available options, and probable results of choosing each of the various courses of action?
- Has the patient been informed about his/her condition?
- How was the patient informed?
- Have all of the treatment alternatives and their possible consequences been discussed with the patient?
- Has the patient had the time to reflect upon the situation and upon possible options?
- Has the patient made a clear statement of his or her wishes?
- Has the patient discussed the situation thoroughly with someone other than the members of the immediate health care team?
- If the patient is not now competent, is he or she expected to regain capacity?
- If the patient lacks decision-making capacity, has she provided a written advance directive or other clear statement that would indicate what his or her wishes were in these circumstances?
- If the patient lacks decision-making capacity, who should act as surrogate?

- C. What are the views of the health care team?
 D. What pragmatic issues complicate the case?

3. *State the dilemma.*

- A. What are the pertinent ethical issues?
 B. Elicit the ethical guidelines and underlying principles that the patient, family, and members of the clinical team are using.

4. *Consider the choices of action.*

- A. Analyze the advantages and disadvantages of each course of action.
 B. What are the reasons for and against alternative plans of care?

5. *Make the decision.*

- A. Meet with the health care team and with the patient or surrogate.
 B. List the alternative for care.
 C. Negotiate a mutually acceptable decision.

Exercises

1. Ethical Issues of Elder Care — The Case of Mr. Lovatch⁵

This exercise is intended to be used as a basic pre-test for knowledge of clinical ethics issues or to begin the discussion of ethical issues.

Facilitator's Notes

- 1. Allow students to read the case.*
- 2. Administer the pre-test.*
- 3. Discuss the answers.*

2. Hypothetical Ethics Cases for Discussion⁸

The Mount Sinai GITT Program as part of their clinical teaching in ethics and team training developed the following hypothetical cases.

3. The Values History Form⁹

The Values History Form recognizes that medical decisions we make for ourselves are based on the beliefs, preferences, and values that matter most to us: How do we feel about independence and control? How do we feel about pain, illness, dying? and death? What in life gives us pleasure? Sorrow? A discussion of these and other values can help clinicians to clarify their personal values.

Facilitator's Notes

- 1. Ask students to complete the form prior to class.*
- 2. Ask students to discuss their answers in-groups of 2-3 students.*
- 3. Students should attempt to separate their personal views from views of their discipline and their organization.*
- 4. Discuss the answers.*

4. Cave Rescue Briefing¹⁰

In this exercise, students as a group must determine which individuals from amongst a group trapped in a cave should be saved. Facilitators should use the exercise to help students identify biases and clarify values that often come into play in a triage situation.

Facilitator's Notes

- 1. Ask students to individually rank the trapped individuals based on their personal values.*

⁸ Developed by Mount Sinai GITT, New York, NY.

⁹ Developed at the Institute of Public Law, University of New Mexico School of Law—not copyrighted.

¹⁰ Adapted by Gloria Heinemann, PhD, Buffalo Veterans Administration Hospital, Interdisciplinary Team Training Program. Buffalo, NY.

2. *Students should attempt to separate their personal views from views of their discipline and their organization.*
3. *Discuss the answers.*

5. Ethical Dilemmas, Teams, and the Locus of Care¹¹

The case of Mrs. Gomez will be examined in four parallel settings: her home, the outpatient clinic, the hospital, and the nursing home. The clinical information and the composition of the team will be approximately the same in each setting, with variations only made in order to make it consistent with the locus of care. Although only minor clinical details will be changed, the entire case is repeated in each section allowing use of any of the four sections of the chapter separately or in another sequence. The cases allow examination of issues of team care as well as the influence of the health care setting on the ethical dilemmas.

Facilitator's Notes

1. *Have groups of two students read a case.*
2. *Have students get together in-groups of four (with two different cases) and identify the differences that the locus of care makes for the treatment of the patient's medical and social issues.*
3. *Discuss the answers.*

¹¹ Cases adapted from: Burck, R., & Rothschild, S., (2000). Locus of care and its effect on ethical conundrums. In M.D. Mezey, C. Cassel, M. Bottrell, K. Hyer, & J. Howe. An ethics casebook in geriatric interdisciplinary team training. Baltimore, MD: Johns Hopkins Press.

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GITT Exercises: Topic 6

Mount Sinai GITT: CASE STUDY- Mr. Lovatch

Mr. Lovatch, 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 left his bed. He has several infections that responded well to therapy. He communicated by whispering and writing. Many staff members observed that Mr. Lovatch seemed depressed. He has never been treated for clinical depression. His spouse of nearly 50 years, Mrs. Lovatch, visited him faithfully during all of his hospitalization. She fed him his lunch and dinner by spoon. She was a much-admired visitor and often brought gifts to the staff. She was a “lovely woman, truly devoted to her husband,” in the words of the staff social worker.

Mr. Lovatch 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. Lovatch’s health care proxy was filed in his chart. In a subsequent discussion with his physician, Mr. Lovatch 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. Lovatch told his primary nurse that “when the time comes, I don’t want one of them feeding tubes. 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. Lovatch and his wife in the room. This time Mr. Lovatch 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, she 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.”

Sample Exam

1. Based on the case of Mr. Lovatch:

- A. What are some ethical issues introduced in this case study?
- B. Who might be persons who could be involved in assisting in this situation?
- C. How would you plan care for Mr. Lovatch based on the information outlined here?
- D. What are any thoughts/feelings that you have about this care situation?

2. Apply a similar ethical analysis framework to that of Mr. Lovatch 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?

True/False

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

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
- 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

Hypothetical Ethics Cases for Discussion

The Mount Sinai GITT Program as part of their clinical teaching in ethics and team training developed the following hypothetical cases.

Case: Mrs. Malvachek: "The Daughter Wants Everything Done"

Mrs. Malvachek is an 89-year-old female who came to the nursing home approximately six months ago following a hospitalization for pneumonia. The underlying condition that most likely caused the pneumonia was end-stage Parkinson's Disease. Mrs. Malvachek was felt to be aspirating during that hospitalization, and a feeding tube was placed prior to her discharge to the nursing home.

Mrs. Malvachek had been living with her daughter for two years prior to hospitalization, and she did not return to the daughter's home because of the feeding tube. Her, other medical problems were osteoporosis with chronic back pain, and a history of colon cancer, treated several years earlier with surgery. Mrs. Malvachek had lived for many years in Florida with a daughter who had died two and one-half years ago from lung cancer.

Shortly after admission, Mrs. Malvachek had another bout of pneumonia, but this time; the chest x-ray also showed what was felt to be metastases from her colon cancer. Mrs. Malvachek's daughter sought out several opinions for treatment, and wanted her mother to have chemotherapy if possible. At that time, Mrs. Malvachek's back pain also' became worse. The pain did not seem to respond to Tylenol, but the daughter refused to let the doctor give her mother anything stronger for pain. The daughter said she felt her mother's, quality of life was dependent on her ability to interact with others, and stronger 'pain pills would sedate her to such an extent that she would be unable to do that. The primary care team responsible for Mrs. Malvachek's care became concerned that the daughter was not making good decisions for Mrs. Malvachek, who seemed to be declining in front of their eyes. The daughter seemed to show no awareness of her mother's multiple medical problems, and was only hoping for a cure. She also started agitating for her mother to sign a health care proxy No one on the team felt the mother had sufficient cognitive ability to do this. Furthermore, they were afraid the daughter would use it to demand aggressive treatments that would only cause Mrs. Malvachek more pain.

This morning, the daughter announced that her mother had a "really good week-end", and had been visited by two friends. And, according to the daughter, while the friends were at her bedside, Mrs. Malvachek signed a health care proxy appointing her daughter as health care agent.

1. How should the nursing home respond to Mrs. Malvachek's daughter?
2. Would you accept this proxy as valid? Why or why not?
3. What options does the nursing home have here?

Case Study: Dr Knuff: "Managing a Physician's Pain"

Dr. Knuff is an 84-year old retired research physician with a history of heart disease and congestive heart failure as well as osteoporosis and breast cancer. She had a right mastectomy several years ago. She came to the nursing home a year ago following a fall, was discharged home in 6 weeks ago, and was admitted again after suffering a heart attack soon after discharge. Her cardiologist thought she was too frail to manage again alone at home, and she reluctantly agreed to placement.

She had been married three times but had no living spouse and no children or any other social supports in the community.

Dr. K's medications included several heart drugs, as well as Percocet for "chest pain".

The Ethics Consult Team was asked to see the patient because the primary care team was concerned she was addicted to the Percocet. She gave a history of having taken Percocet for several years at home, but was unclear as to exactly why it was started. She only knew that she needed it to treat a pain that she described as a squeezing pain around her lower chest, which made her short of breath, and increased, when she took a deep breath. She thinks the pain had been diagnosed as osteoporosis in the past, and that she may have been given Percocet for that. She may have also been given it following her mastectomy

On physical exam, there was no obvious chest wall pathology and she refused spine x-rays or a bone scan to look for causes for the pain. To see if the pain was real, the primary care physician put the patient on placebo Percocet, and the patient reported continued relief.

1. How should this patient be managed?
2. Should placebos be continued?
3. Should she be confronted with the feeling that her pain is not significant and that she may be addicted to Percocet?

Case: Ms. Krisp: "Truth-Telling and the Cognitively Impaired Resident"

Ms. Krisp is a 97-year-old nursing home resident. Although she is mildly demented, she is quite alert and has a pleasant personality and is a favorite among the nursing staff.

One of Ms. Krisp's daughters, Ms. Rodriques, had been very active in the community and was president of the nursing homes friends and relatives organization. Ms. Rodriques and her mother had a close relationship and Ms. Rodriques visited her mother on a regular basis. Ms. Rodriques like her mother was well liked by the nursing home staff. The rest of Ms. Krisp's family has also been very caring and involved with Ms. Krisp.

About a month ago, Ms. Krisp's daughter, Ms. Rodriques, was diagnosed with cancer and died within a few weeks. Ms. Krisp's family was very concerned about the effect this death would have on Ms. Krisp, and they insisted that she not be told about her daughter's illness or death. They said that this news would kill her. Whenever Ms. Krisp has asked for her daughter, she was told that Ms. Rodriques is away on business.

The staff was very concerned that Ms. Krisp would inadvertently overhear conversations about her daughter's death from others. The family suggested that they take away her hearing aids to prevent this from occurring. The staff agreed with this suggestion and removed the hearing aids and left them at the nurses' station.

Upon further discussion with the family, it is learned that they are not totally opposed to telling her about her daughter's death, but felt too overwhelmed to discuss it with her themselves. They also reiterated their fear that the news would be such a shock to Mrs. Krisp that it could potentially result in her imminent death.

1. What ethical principles do you think are influencing the decisions of the individuals involved in this case?
2. What ethical principles should take precedence? Why?
3. What would you do to resolve this issue?

Case: Ms. Master: “Are Health Care Decisions Written in Stone?”

Mr. Master is an 88-year old man who was admitted to the nursing home from an acute care hospital where she had been taken when she suffered a stroke. Prior to this, he lived alone at home and was extremely independent. Mr. Master had never married and had no children, but had a number of very close friends who were very involved with her care.

Upon admission to the nursing home, Mr. Master was found to have a global aphasia. He also had a history of atrial fibrillation and left ventricular hypertrophy, and a gastrostomy tube in place.

After several weeks in the nursing home, a team meeting was held to discuss Mr. Master. Two of his closest friends were invited to the meeting—Mr. Lincoln and Ms. Greene—Mr. Master attended part of the meeting as well. Prior to the meeting, Mr. Master's friends expressed a concern to the staff about the presence of the gastrostomy tube. They had agreed to its insertion while Mr. Master was hospitalized because his physician in the hospital had convinced them that there was an urgent need for artificial nutrition. They report that this was presented to them as if they had no option. After some thought, however, they questioned whether they had made the right decision, based on the wishes Mr. Master had expressed in her living will and health care proxy. They felt that Mr. Master was a very strong-willed, feisty individual who valued his independence, and they questioned whether he would have gone along with the decision to insert a feeding tube had she been able to make the decision at the time.

At the meeting, Mr. Master's friends brought up their discomfort with Mr. Master having the feeding tube, and asked the team members if they felt the gastrostomy feedings be discontinued, in keeping with the statements in Mr. Master's living will. Although the team was aware of the contents of the living will, they were unanimous in their feeling that Mr. Master had improved significantly since admission. They felt he was adapting extremely well to the nursing home environment, and appeared to them to be content. They suggested maintaining the tube, in hopes that Mr. Master's ability to eat by mouth might return. After a few months, oral feedings were re-introduced to Mr. Master, and he tolerated them well.

Over time, Mr. Master's adjustment to the home continued. He appeared to get along well with her roommate, as well as most of the other residents on the unit. He propelled himself in his wheelchair from one end of the unit to the other, and regularly participated in activities. Although he remained unable to speak, he was able to make many of her wishes known to staff and his visitors.

About one year later, Mr. Master was the subject of an annual review at a team meeting, which he was in attendance, along with his two friends. The team noted that Mr. Master's living will indicated that he would not want resuscitation attempted should she experience cardiac arrest. However, there was no DNR order in her chart. The team questioned Mr. Master as to his wishes, and the entire team, along with Mr. Master's friends, agreed that Mr. Master was clearly indicating to them that he would prefer that CPR be initiated if need arose. His friends reiterated their view that Mr. Master had the ability to communicate what he wanted. They gave as an example what Mr. Master did when he wanted visitors to leave; he pointed at the clock, then pointed at the visitors, then pointed at the door. The team took this as additional evidence that Mr. Master did, indeed, have the ability to express his preferences, but were troubled by the fact that what he was saying was counter to what the living will stated regarding resuscitation.

1. How would you handle this case?

Case: Ms. S: "Consensual Sex and the Resident with Alzheimer's Disease"

Ms. Sylvan is an 83 year old female with a primary diagnosis of Senile Dementia of the Alzheimer's Type. She is alert and acknowledges people with facial expressions, but is not verbal. She is wheelchair-bound, but propels herself from her room to the dining room. She feeds herself, but is dependent in all other Activities of Daily Living. She has elderly relatives who seldom visit. She has been a resident of the Home for approximately 5 years.

Recently, Ms. Sylvan has been seen in the dining room between meals apparently engaged in oral sexual activity with a male resident, Mr. Rubens. He was admitted to the Home six months ago following a stroke that rendered him paralyzed on his left side. He, too, is wheelchair-bound but can propel himself as Ms. Sylvan does. Unlike Ms. Sylvan, however, he is not demented and is also married. His wife visits approximately once a week.

The staff at first does not know how to react to this situation. Ms. Sylvan seems perfectly content and does not appear coerced. Mr. Rubens also seems to be enjoying these encounters. Their initial concern is for the other residents who might be offended by such behavior taking place in public, and social service and nursing ask Mr. Rubens to limit this activity to the privacy of his room, as he is the one with whom they can still communicate. Soon, however, other questions arise. With Ms. Sylvan's diagnosis of dementia, can these sexual relations really be consensual? What about Mr. Ruben's wife? And even if she is not bothered by her husband's sexual activities, should the Home condone sexual relations between a married man and someone else who is not his wife?

The primary care team asks for an ethics consultation.

1. How would you respond to their questions?
2. What other issues would you identify in this case?
3. What other information would be helpful, in addition to that provided?
4. What do you feel is the best resolution in this situation?

The Values History Form

Why a Values History Form?

The Values History Form recognizes that medical decisions we make for ourselves are based on the beliefs, preferences, and values that matter most to us. How do we feel about independence and control? About pain, illness, dying, and death? What in life gives us pleasure? Sorrow? A discussion of these and other values can provide important information for those who might, in the future, have to make medical decisions for us when we are no longer able to do so.

Further, a discussion of the questions asked on the Values History Form can provide a solid basis for families, friends, physicians, and others when making medical decisions. By talking about these issues ahead of time, family disagreements may be minimized. And when decisions do need to be made, the burden of responsibility may be lessened because others feel confident of your wishes.

How do I fill out the Values History Form?

The Values History Form asks a number of questions about issues such as your attitude toward your health, your feelings about your health care providers, your thoughts about independence and control, personal relationships, your overall attitude toward life, your attitude toward illness/dying/death, your religious background and beliefs, your living environment, your attitude toward finances, and your wishes concerning your funeral. Simply answer the questions. The form also allows you to record both written and oral instructions you might already have prepared.

There are a number of ways in which you might begin to answer these questions. Perhaps you would like to write out some of your own thoughts before you talk with anyone else. Or you might ask family and friends to come together and talk about your -- and their -- responses to the questions.

Often, simply making copies of the Values History Form available to others is enough to get people talking about a subject that, for many of us, is difficult and painful to consider. The most important thing to remember is that it is easier to talk about these issues BEFORE a medical crisis occurs. Feel free to add questions and comments of your own to those already provided.

What should I do with my completed Values History Form?

Make certain that all those who might be involved in future medical decisions made on your behalf are aware of your wishes: family, friends, physicians, other health care providers, your lawyer, and your pastor. If appropriate, provide written copies to these people. But remember that each of us continues to grow and change, and so the Values History Form should be discussed and updated regularly, as preferences and values evolve. Consider attaching a copy of it to your Living Will, Durable Power of Attorney, or Advance Directive for Health Care, if you have one, or filing the Values History Form with your important medical papers.

Who should consider preparing a Values History Form?

Everyone. While it has been customary to focus on older people, it is just as important that younger people discuss these issues and make their wishes known. Often, some of the most difficult medical decisions must be made on behalf of younger patients. If they had talked with families and friends, these decision-makers could feel reassured they were following the patient's wishes.

What if I do not have a Living Will or Durable Power of Attorney for Health Care?

Whether you sign either of these is entirely up to you and laws governing these vary from state to state. For information and assistance, the following agencies might be of help:

Concern for Dying/Society for the Right to Die 250 West 57th Street, New York, NY 10107 (212-246-6973).

This agency will provide legal information about Living Wills and Durable Powers of Attorney for Health Care, as applicable in your own state. Please write to them at the above address. Because of the recent large volume of requests, expect a 4-6 week turnaround time. If you have an emergency, you may telephone them, but they caution that it is very difficult to get through on the telephone.

American Association of Retired Persons.

For a single, free copy of the Health Care Power of Attorney booklet, please send a postcard with your name and address to: AARP Fulfillment (Stock No. D13895), 1909 K Street, N.W., Washington, D.C. 20049

You might also contact your local Office of Senior Affairs, your state or area agency on aging, agencies providing legal services for the elderly, or your personal attorney.

We hope this Values History Form is of help to you, your family, and friends. Many people have commented that it is important to reflect not so much on "how I want to die," but rather on "how I want to LIVE until I die."

The Values History Form ¹²

The form is not a legal document, although it may be used to supplement a Living Will, a Durable Power of Attorney for Health Care, or an Advance Directive for Health Care, if you have these.

NAME:

DATE:

If someone assisted you in completing this form, please fill in his or her name, address, and relationship to you.

Name:

Address:

Relationship:

It is important that your medical treatment be your choice.

The purpose of this form is to assist you in thinking about and writing down what is important to you about your health. If you should at some time become unable to make health care decisions, this form may help others make a decision for you in accordance with your values.

The *first section* of this form provides an opportunity for you to discuss your values, wishes, and preferences in a number of different areas such as your personal relationships, your overall attitude toward life, and your thoughts about illness.

The *second section* of this form provides a space for indicating whether you have completed an Advance Directive, e.g., a Living Will, Durable Power of Attorney for Health Care Decisions, or Advance Directive for Health Care, and where these documents may be found.

This form is not copyrighted; you may make as many copies as you wish.

First Section:

Overall attitude toward life and health

1. What would you like to say to someone reading this document about your overall attitude toward life?

2. What goals do you have for the future?

¹² Value History Form is developed by the Center for Health Law and Ethics, Institute of Public Law, University of New Mexico School of Law, 1117 Stanford NE, Albuquerque, New Mexico 87131.

3. How satisfied are you with what you have achieved in your life? What, for you, makes life worth living?
4. What do you fear most? What frightens or upsets you?
5. What activities do you enjoy (e.g., hobbies, watching TV, etc.)?
6. How would you describe your current state of health?
7. If you currently have any health problems or disabilities, how do they affect: You? Your family? Your work? Your ability to function?
8. If you have health problems or disabilities, how do you feel about them? What would you like others (family, friends, doctors) to know about this?
9. Do you have difficulties in getting through the day with activities such as: eating? preparing food? sleeping? dressing and bathing? etc.
10. What would you like to say to someone reading this document about your general health?

Personal relationships

1. What role do family and friends play in your life?
2. How do you expect friends, family, and others to support your decisions regarding medical treatment you may need now or in the future?

3. Have you made any arrangements for family or friends to make medical treatment decisions on your behalf? If so, who has agreed to make decisions for you and in what circumstances?
4. What general comments would you like to make about the personal relationships in your life?

Thoughts about independence and self-sufficiency

1. How does independence or dependence affect your life?
2. If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency?
3. If your current physical or mental health gets worse, how would you feel?

Living environment

1. Have you lived alone or with others over the last 10 years?
2. How comfortable have you been in your surroundings? How might illness, disability, or age affect this?
3. What general comments would you like to make about your surroundings?

Religious background and beliefs

1. What is your spiritual/religious background?
2. How do your beliefs affect your feelings toward serious, chronic, or terminal illness?

3. How does your faith community, church, or synagogue support you?
4. What general comments would you like to make about your beliefs?

Relationships with doctors and other health caregivers

1. How do you relate to your doctors? Please comment on: trust; decision making; time for satisfactory communication; respectful treatment.
2. How do you feel about other caregivers, including nurses, therapists, chaplains, social workers, etc.?
3. What else would you like to say about doctors and other caregivers?

Thoughts about illness, dying, and death

1. What general comments would you like to make about illness, dying, and death?
2. What will be important to you when you are dying (e.g., physical comfort, no pain, family members present, etc.)?
3. Where would you prefer to die?
4. How do you feel about the use of life-sustaining measures if you were: suffering from an irreversible chronic illness (e.g., Alzheimer's disease)? A terminal illness? In a permanent coma?
5. If you were terminally ill, would you want hospice services to ensure optimal pain and symptom management and support for your family and loved ones?

6. What general comments would you like to make about medical treatment?

Finances

1. What general comments would you like to make about your finances and the cost of health care?
2. What are your feelings about having enough money to provide for your care?

Funeral plans

1. What general comments would you like to make about your funeral and burial or cremation?
2. Have you made your funeral arrangements? If so, with whom?

Optional questions

1. How would you like your obituary (announcement of your death) to read?
2. Write yourself a brief eulogy (a statement about yourself to be read at your funeral).
3. What would you like to say to someone reading this Values History Form?

Second Section

Legal documents

1. What legal documents about health care decisions have you signed?

A. Living Will? ___ Yes ___ No

If yes, where can it be found?

Name

Address

Phone Number.

B. Durable Power of Attorney for Health Care Decisions? ___ Yes ___ No

If yes, where can it be found?

Name

Address

Phone Number.

C. Advance Directive for Health Care? ___ Yes ___ No

If yes, where can it be found?

Name

Address

Phone Number.

D. Other? ___ Yes ___ No

If yes, where can it be found?

Name

Address

Phone Number.

Cave Rescue Briefing

Your group is responsible for a research project on "Human Behavior in Confined Spaces." Your six volunteers have been trapped underground in a cave. Water is rising rapidly in the cave, and the rescue squads tell you that only one person per hour can be brought out. The volunteers have asked that you make the decision on who will be rescued. Unfortunately, all the information you have is limited to the brief biographical data reproduced here. You must provide the rescue squad with a rank order for rescuing the trapped volunteers before the rescue equipment arrives in 50 minutes.

CAVE RESCUE BIOGRAPHICAL SHEET

Volunteer 1. Helen: White, Female, American, Age 34

Helen is married and a homemaker. Her husband is a member of the city council. She had been a promising psychology student before leaving the university to be married. Helen has four children (aged 7 months to 8 years) and lives in a pleasant suburban community near the university. Her hobbies are ice skating and cooking. Helen became involved in the experiment through Owen, with whom she has developed a covert sexual relationship.

Volunteer 2. Tozo: Oriental, Female, Japanese, Age 19

Tozo is single and a sociology student at state university. Her wealthy Japanese parents live in Tokyo where her father is an industrialist and a national authority on traditional Japanese Mime Theater. Tozo is outstandingly attractive and has several "upper-crust" boyfriends. She recently was among several women featured in a television documentary on Japanese womanhood

Volunteer 3. John: Black, Male, American, Age 41

John is married and campus coordinator of Catholic Social Services at state university. He has five children (aged 6 years to 19 years). John worked full-time while attending the university, and he earned a master's degree in social work. For many years, he has been deeply involved in a militant black civil rights group. His hobbies are photography and camping out with his family.

Volunteer 4. Owen: White, Male, American, Age 27

Owen is unmarried and a physical education instructor at university high school. He joined the army after high school and became an infantry platoon leader in Vietnam where he received several distinguished decorations. He was sent home with a serious leg wound from which he has recovered (except for occasional pains). He used his GI Bill benefits to earn a master's degree in physical education. Since returning to civilian life, Owen has been unsettled and his drinking has become a persistent problem. His recreation is modifying and driving stock cars.

Volunteer 5. Paul: White, Male, English, Age 47

Paul is divorced and a medical research scientist at the university hospital. He is recognized as a world authority on the treatment of rabies. Paul is testing a new, experimental low-cost rabies treatment, but much of the research data are still in his working notebooks. His hobbies are classical music and sailing. Paul's ex-wife is happily remarried, but in the 6 years since the divorce, he has experienced some emotional difficulties. He has no children. He was twice convicted of indecent exposure (the last occasion was 11 months ago).

Volunteer 6. Edward: White, Male, American, Age 59

Edward is married and has two grown children who have moved away to large cities and have their own families. He is general manager of a small factory that produces rubber belts for machines. The factory employs 71 persons. Edward has personally negotiated a large contract for his company and final contract details are awaiting his return to work. Active socially and politically in the community, Edward is a senior freemason and a member of the city council. His hobby is spelunking (exploring caves), and he intends to write a book about the subject when he retires.

Rush GITT: Ethical Dilemmas, Teams and the Locus of Care

The case of Mrs. Gomez will be examined in four parallel settings: her home, the outpatient clinic, the hospital, and the nursing home. The clinical information and the composition of the team will be approximately the same in each setting, with variations only made in order to make it consistent with the locus of care. Although only minor clinical details will be changed, the entire case is repeated in each section allowing use of any of the four sections of the chapter separately or in another sequence. The cases allow examination of issues of team care as well as the influence of the health care setting on the ethical dilemmas.

Case #1: Team Care of Ms. Gomez at Home

Lucy Gomez is an 85-year-old widowed Hispanic woman who lives alone in a ramshackle apartment (in the view of team members who have been there) in an inner city neighborhood. For the past 5 years, she has received care from a primary health care team, which provides services in her home. Members of the team include a GNP, physician, SW, OT, and chaplain.

Mrs. Gomez has been fairly independent in her self-care, although she does not go out very often. She pays a neighbor to pick up her medicines and groceries. Her medical problems include hypertension and diabetes; both of these have been fairly well-controlled with medications. She has had very mild dementia (MMSE of 22 out of 30) for the past 2 years, without identified reversible causes.

The nurse practitioner came to see Mrs. Gomez after she received a call from the patient's niece, who lives across town. The niece was upset because Mrs. Gomez had fallen five times in the past 2 weeks. Recently when she stopped to visit, she found her aunt sitting on the floor in the bathroom, unable to get up without extensive help from the niece.

She was found to have lost 15 pounds since the prior visit 3 months ago. A small abrasion that she had on her left shin is now a Stage III ulcer, with poor healing. Mrs. Gomez appeared disheveled and dehydrated. She was very deconditioned and could not stand without full assistance of two people.

Mrs. Gomez refused to go to the hospital then. She was given 1 liter of IV fluids in the home and blood tests were performed. Social work arranged for 4 hours of a home health aide, five times a week, from the city department of aging. PT and OT began to work with the patient, coming to her home several times a week. No new pathology was found after a thorough workup.

Two weeks later, her condition is unchanged. More frustrating to clinicians is the nurse practitioner's report of Mrs. Gomez's her poor effort and follow-through on exercises and oral intake. She also refuses to have any family move in with her because she believes they will steal from her. The team is concerned for her safety if she remains in the home by herself. Despite her dementia, however, she appears to understand her situation and refuses to go to a nursing home:

"I know you all are trying to help me and are worried about me and all. I'm worried about falling too. I'd like to have help but I'm afraid they would steal from me. My niece says I can come live

with her...but this place means so much... and I don't really trust her, either. No, the only way I am leaving this house is going to be in a box."

The challenges that Ms. Gomez presents to the team in her home:

- She is falling at home and at times may be unable to get up or ask for help.
- She is deconditioned, dehydrated, and may be malnourished, but she refuses to go to a hospital.
- She needs closer supervision, but she refuses either having family move in with her or moving to a nursing home herself.
- She has a responsibility to exercise and to eat enough, but she is not doing so.
- She is able to tell clinicians accurately the nature and consequences of her decisions, but her decisions continue to harm her.
- She apparently wishes to be considered a decision-making member of the health care team, but she acts more like a recipient of care than an actor on her own behalf.

Questions to consider about the team in the home:

- In the home setting, teams may be subtly biased towards therapeutic nihilism, or at least towards unquestioning acceptance of the patient's position. How can the team avoid either of these biases?
- How would the issues, including the goals of medicine, raised by this case be different if Mrs. Gomez had moved into this home within the past 6 months?
- How would the issues be different if Mrs. Gomez was living in her niece's home?

Case #2: The Team in the Primary Care Clinic

Lucy Gomez is an 85-year-old widowed Hispanic woman who lives alone in a ramshackle apartment in an inner city neighborhood. For the past 5 years she has received care at a nearby community health center. This outpatient clinic uses a team of clinicians to care for frail elderly, including a GNP, physician, SW, OT, and chaplain.

Mrs. Gomez has been fairly independent in her self-care, although she does not go out very often. She pays a neighbor to pick up her medicines, and groceries. Her medical problems include hypertension, and diabetes; both of these have been fairly well controlled with medications. She has had very mild dementia (MMSE of 22 out of 30) for the past 2 years, without identified reversible causes.

Mrs. Gomez has come in for her regular follow-up appointment, brought in by her niece, who lives across town. The niece was upset because Mrs. Gomez had fallen five times in the past 2 weeks. Recently when she stopped to visit, she found her aunt sitting on the floor in the bathroom, unable to get up without extensive help from the niece. When asked about this directly, Mrs. Gomez denied having a problem, saying "everybody slips once in awhile; it's not so bad."

She was found to have lost 15 pounds since the prior visit 3 months ago. A small abrasion that she had on her left shin is now a Stage III ulcer, with poor healing. Mrs. Gomez appeared disheveled and dehydrated. She was very deconditioned and could not stand without full assistance of two people.

Mrs. Gomez refused to go to the hospital then. She was given IV fluids in the clinic, and blood tests were performed. Social work arranged for 4 hours of a home health aide, five times a week, from the city department of aging. PT and OT began to work with the patient, coming to her home several times a week. No new pathology was found after a thorough workup.

Two weeks later, her condition is unchanged. More frustrating to the team is her poor effort and follow-through on exercises and p.o. intake. She also refuses to have any family move in with her because she believes they will steal from her. The team is concerned for her safety if she remains in the home by herself. Despite her dementia, however, she appears to understand her situation and refuses to go to a nursing home:

“I know you all are trying to help me and are worried about me and all. I’m worried about falling too. I’d like to have help but I’m afraid they would steal from me. My niece says I can come live with her...but this place means so much... and I don’t really trust her, either. No, the only way I am leaving this house is going to be in a box.”

The challenges that Ms. Gomez presents to the team in the clinic:

- She is falling at home, but at times may be unable to get up or ask for help.
- She is deconditioned, dehydrated, and may be malnourished, but she refuses to go to a hospital. She has, however, come to the clinic, and has cooperated with outpatient evaluation.
- She needs closer supervision, but she refuses either having family move in with her or moving to a nursing home herself.
- She has a responsibility to exercise and to eat enough, but she is not doing so.
- She is able to tell clinicians accurately the nature and consequences of her decisions, but her decisions continue to harm her.
- She apparently wishes to be considered a decision-making member of the health care team, but she acts more like a recipient of care than an actor on her own behalf.

Questions to consider about the team in the outpatient clinic:

- How could team members respond if the physician says “It’s all well and good for you to advocate for the patient’s rights, but I’m the one that her niece is going to sue if Mrs. Gomez dies at home!”
- The mission of this team is not explicitly stated in the case study. How would the analysis of the case change if the primary care team has been formed for each of the following purposes:
 - To help control clinic costs of providing health care to frail seniors.
 - To promote patient autonomy and quality of life.
 - To reduce incidence of premature morbidity and mortality through risk factor identification and reduction.

Case #3: Team Care of Mrs. Gomez in the Hospital

Lucy Gomez is an 85-year-old widowed Hispanic woman who lives alone. She was admitted to the University Hospital after her niece reported that she had fallen five times in the past 2 weeks. On the morning of admission, the niece had stopped to visit Mrs. Gomez, and she found her sitting on the floor in the bathroom, unable to get up without extensive help from the niece. It was not clear if she had sustained a syncopal episode.

The Acute Care Geriatrics Unit utilizes an interdisciplinary team approach to patient care. Members of the team include a physician, GNP, SW, OT, and dietician.

Mrs. Gomez's medical problems include hypertension and diabetes; both of these have been fairly well-controlled with medications. According to outpatient records, she has had very mild dementia (MMSE of 22 out of 30) for the past 2 years, without identified reversible causes. The niece also mentioned that she was concerned because the patient ate poorly, and had probably lost 10 to 15 pounds in the past 3 months.

On exam, the patient was obese and in no distress. Skin exam revealed a 4 cm by 6 cm Stage III ulcer, with poor healing. Mrs. Gomez appeared disheveled and dehydrated. She was very deconditioned and could not stand without full assistance of two people. The remainder of her exam was normal.

She was started on IV fluids in the home, and antibiotics for possible occult infection. PT and OT evaluated her and began daily exercise. Blood tests were performed, as well as a CT scan of the brain; these are non-contributory.

After 4 days in the hospital, Mrs. Gomez's condition is unchanged. More frustrating to the team is her poor effort and follow-through on exercises and p.o. intake. She told the discharge planner adamantly that she refused to have any family move in with her because she believes they will steal from her. She is refusing nursing home placement, either short-term or long-term.

The team is concerned for her safety if she returns home by herself. Despite her dementia, however, she appears to understand her situation and refuses to go to a nursing home:

"I know you all are trying to help me and are worried about me and all. I'm worried about falling too. I'd like to have help but I'm afraid they would steal from me. My niece says I can come live with her...but my house means so much... and I don't really trust her, either. I have to go home, I can't stay in this place anymore."

The dilemmas that Ms. Gomez presents the team in the hospital:

- She has been admitted to the hospital because she has been falling at home, and is deconditioned, dehydrated, and may be malnourished.
- She agreed to an inpatient admission and has not refused testing. At the same time, she has a responsibility to exercise and to eat enough, but she is not doing so.
- She is able to tell clinicians accurately the nature and consequences of her decisions but her decisions continue to harm her.
- Based on her behaviors and function in the hospital, the team believes she is at risk of injury if she returns home.
- She apparently wishes to be considered a decision-making member of the health care team, but she acts more like a recipient of care than an actor on her own behalf.

Questions to consider about the hospital-based team:

- How can an interdisciplinary team working in a hospital setting ensure that the patient is an active part of the team?
- What are the risks of the team assuming a role as patient advocate in confrontation with other staff in the hospital? What are the benefits?

- What processes can a hospital-based team put into place to ensure equal participation among members?
- Some hospitals have adopted a “hospitalist” model of care in which only the physician takes care of the patient while he or she is in the hospital? How might such a model impact team function?

Case #4: Team Care of Mrs. Gomez in the Nursing Home

Lucy Gomez is an 85-year-old widowed Hispanic woman who moved to the nursing home 2 weeks ago, after being discharged from the hospital following a series of falls. The nursing home has been using an interdisciplinary team for SNF patients who are admitted from the hospital. Members of the team include a GNP, SW, PT and OT, a skin care nurse, and a psychiatrist.

According to her niece, until recently Mrs. Gomez had been fairly independent in her self-care, although did not go out very often. She paid a neighbor to pick up her medicines, and groceries. Her medical problems include hypertension and diabetes; both of these have been fairly well controlled with medications. She has had very mild dementia (MMSE of 22 out of 30) for the past 2 years, without identified reversible causes.

Mrs. Gomez had been admitted to the hospital after falling five times in a 2-week period. According to the hospital records, Mrs. Gomez was grossly deconditioned but no cause was found for her weakness and anorexia.

Since transferring to the nursing home 2 weeks ago, Mrs. Gomez has made little progress. She has gained only 1 pound, despite being presented with high caloric foods. Despite PT and OT twice a day, she has shown little willingness to try to walk and move about. A Stage III ulcer on her left shin is healing very slowly, despite the aides giving her a whirlpool bath every day and providing careful wound care.

The staff nurses in the nursing home are upset because Mrs. Gomez has tried to get up on her own almost every day, and on four occasions nearly fell. They have received an order from her attending to put a restraint vest to reduce the risk of falls.

When the team met to review her case, they were concerned about her discharge plans. She has made few gains that would justify further SNF care; team members believe she should be moved to the long-term care wing of the nursing home. Mrs. Gomez insists that she wishes to return home, despite her lack of safety and frequent falls. She has told the social worker that she refuses to have any family move in with her because she believes they will steal from her. The team is very concerned for her safety if she returns home by herself. Despite her dementia, however, she appears to understand her situation and refuses to remain in the nursing home:

“I know you all are trying to help me and are worried about me and all. I’m worried about falling too. I’d like to have help but I’m afraid they would steal from me. My niece says I can come live with her...but my house means so much... and I don’t really trust her, either. I have to go home, I can’t stay in this place anymore.”

The dilemmas that Mrs. Gomez presents the team in the nursing home:

- She had been admitted to the hospital because she of falling at home, reconditioning, dehydration, and malnutrition.

- Despite the hospital admission and rehabilitative efforts in the nursing home, she has not improved significantly. She has a responsibility to exercise and to eat enough but she is not doing so.
- She is able to tell clinicians accurately the nature and consequences of her decisions but her decisions continue to harm her.
- Her behaviors and function in the nursing home put her at risk of injury due to falls. Her continued efforts at getting up are disruptive to the nursing home, and raises concerns about the staff's liability if she falls.
- Based on her behaviors and function in the nursing home, the team believes she is at risk of injury if she returns home; however, it is not clear that being in the nursing home reduces her risk of fall and injury.
- She apparently wishes to be considered a decision-making member of the health care team, but she acts more like a recipient of care than an actor on her own behalf.

Questions to consider about the nursing home team:

- Mrs. Gomez cannot be held as a prisoner in the nursing home. What options does this team have if she announces her plan to go home in a day or two?
- Although this team has the benefit of time, what is a reasonable time limit for resolving these issues?

If Mrs. Gomez continues to have periodic falls despite participating in the team's treatment plan over the course of a year and still insists she wants to go home anyway, has the team violated her autonomy?

