



Ethics Committee Handbook — For New Members Orientation

by Rosemary Flanigan

Center for Practical Bioethics
1111 Main Street, Suite 500
Kansas City Missouri 64105-2116
www.practicalbioethics.org
bioethic@practicalbioethics.org

CONTENTS

Introduction 1

Morality and Ethics 7

The Changing Face of Medicine 12

Educating Ourselves and Others 16

Case Consultations 21

Policy Review and Development 27

 Sample Policy:

 Considerations Regarding Withholding/
 Withdrawing Life Sustaining Treatments 31

Conclusion 38

Introduction

You have been asked to serve on an ethics committee. Congratulations. This manual will introduce you to your new responsibilities and help orient you to the role ethics committee members assume in their healthcare organizations. You, your hospital, and the patients and families it serves, will benefit immensely from your participation on the committee. Before we start, however, consider the following scenarios:

Your Baby Sister Has a High Fever

In 1930, your mother would have given her half an aspirin and if the fever continued to rage, she might have called the family doctor. Night or day, he would have come to the house (at night, most probably in his slippers) and prescribed her care. If the child needed to be hospitalized, the doctor might himself have taken her there.

In 2003, your mother wraps her up, puts her in the car, and drives her to the nearest ER; or she calls 911 and the ambulance arrives at the door in minutes. Your parents may ride along, but they will be asked to wait while strangers care for your sister.

Grandma Is Dying

In 1930, Grandma would probably be living with one of her children and been an important part of the family. When her health worsened, the doctor might have come to the house, more as a social than a professional visit. He might have comforted the family, held Grandma's hand; and when she died, she would do so in her bed, surrounded by her family. Grandma's physician and

the family's clergy might have joined the family in the kitchen after her death, to drink coffee and tell stories about her past or simply to help the family grieve.

In 2003, Grandma is probably residing in a nursing home, and may have been there for several months or even as long as two years. One of the aides will notice her decline and report it to the nurse on duty. The nurse on duty will then look in on Grandma, and determine whether the family should be called. The medical director may tell the nurse to call 911 to take Grandma to the hospital. Resuscitation may be attempted and Grandma may be isolated in the intensive care unit for some days before death comes.

Or, perhaps Grandma is still living on her own when she begins to fail. In that case, a neighbor may call 911 (or Grandma's family, if she has any). An ambulance whisks Grandma off to the hospital which, in turn, rushes Grandma into intensive care. There she will die with more or less clinical intervention in her dying.

What Do Those Scenarios Tell Us?

In fewer than sixty years, the practice of medicine has changed dramatically. The most dramatic characteristics are the following:

- The physician, who had been sole decision maker, has become part of a healthcare team.
- Medicine, which had been limited in what it could do, has become linked to technology,

which has revolutionized its practice.

- A half-century ago, nature often “took its course,” but now its course is radically altered with multiple options from which to choose.
- A death in the family has become a death in the hospital or long-term care facility where it is clinically “managed.”
- For many patients, there may be no primary care provider, and members of the healthcare team will likely be strangers to the patient and his or her family.

Ethics committees have been established to help the injured, the ill, and the dying recipients of healthcare — and their families — evaluate their options. And, no less important, ethics committees are empowered to help healthcare providers as well as patients fulfill their roles and responsibilities in a technological and complicated age.

This orientation manual will introduce you to ethics and provide samples of thinking through issues ethically. It will introduce you to the history of medicine vis-à-vis ethics committees and present the three areas in which ethics committees are most active: education, case consultation, and

policy development or review, with examples of each one. Here, as in so many other areas of life, practice makes perfect. Let us begin.

Benefits of Using this Manual

When you have completed this manual, you will be able to exercise the following skills:

- apply ethical analysis to distinguish between facts and values;
- distinguish between three types of moral arguments: utilitarian (consequences), principle (duty-based), or virtue ethics;
- identify and describe the roles and responsibilities of ethics committees;
- plan a course for continuing your education in ethics and ethical analysis;
- understand the organization of ethics committees and differentiate between various models of case consultation; and
- use your new knowledge to help your committee help patients, their families, and healthcare providers establish meaningful communication and solve ethical problems.

Chapter 1 — Morality and Ethics

Each of us acts morally, or immorally, on occasion. We have learned the difference between right and wrong or good and bad actions, and strive to do good, at least most of the time. The term morality refers to our intentions and behaviors; the term ethics refers to the reasons for or against acting in a certain way. When ethics committees are asked to help others determine what is the morally right thing their tool of choice will be ethical analysis. This chapter will help you develop the skill of ethical argument.

Before we consider the work of an ethics committee, we must distinguish morality from ethics.¹ Morality is that collection of behaviors that we have come to learn as being “right” or “good,” “wrong” or “bad.” We learned these morals from our parents or from whoever loved us enough to rear us. We learned “the right thing to do” from their example and by rules they repeated over and over. How often we heard these adults tell us, “Don’t lie,” “Don’t cheat,” “Don’t steal,” and “Don’t spit on your sister.” And when we saw those rules borne out in practice by parents who did not lie, cheat, spit, or steal, we received a deep impression in our moral consciousness.

We are always developing our moral sense, and the best way to know whether or not we are morally healthy is by examining our moral habits. Think back to the time when we were children and we heard our mothers say, “Don’t talk back to me.” We called that “sassing,” and we were in the process of developing a habit of not “sassing” our mothers. Then, a new playmate moved in down the street. What we remember about our new companion-friend is that he was loads of fun

to play with and that he sassed his mother up one side and down the other. She thought it was cute! She even patted him on the head when he did it! So back home we went with our new knowledge that everyone didn’t think sassing was wrong. We tried acting like our new friend when we arrived home — and got sent to bed without supper! That was the beginning of our coming to see that everyone’s morals were not the same.

Our Morals Mature

As we matured, so did our morals. Instead of following the example and rules of our parents simply because they were our parents, we began to make those behaviors and rules our own. For example, my habit of not stealing became deeper and firmer than ever, but if I were asked why I didn’t steal, I did not answer, “Because my mother told me not to.” That answer sufficed when I was small, but now I do not steal because stealing is an unjust act against my neighbors, taking something from them which they own and have a right to keep.

Consider some of the moral rules you learned at home. What makes them “moral” is that they affect your very character. They make you the kind of person you are: generous and loving, a good friend, someone who can be counted on in a crisis, a hard worker for whatever will benefit another. We are defined by our moral character, not by our size, weight, hair style or “personality.”

Suppose, for example, that when you were very young, your mother told you, “Never leave your

room with your bed unmade.” Day after day she repeated that rule and asked if you had obeyed it. Because you were young, you saw that rule as a moral rule, like “Don’t lie,” “Don’t cheat,” “Don’t steal.” And maybe it wasn’t until you had left home that you realized that your mother’s rule about making your bed wasn’t a moral rule, but a neatness rule. She loved her home neat and when the door of your room stood open in the morning, she wanted to have that bed made.

When you left home, you may or may not have followed that rule; but whether you did or not, it had no consequences for your character, though it might have affected your “personality.” But I would be willing to bet that if you go home for a visit and stay overnight, you will make your bed in the morning! Now you fulfill your mother’s wishes, not because neatness is a moral value, but because respect for your mother is.

It is necessary to think about the developing of our moral consciousness because doing ethics depends on having a moral sense. Ethics is attempting to explain our moral judgments by identifying the reason we hold such judgments to be good and the actions they direct us to do as right.

The Meaning of Morality — Questions for Discussion

1. In the development of your own moral sense, who were your principal teachers?
2. Give examples of right and wrong actions that you learned from the example of these moral mentors.
3. Give examples of the rules you were taught for knowing the difference between right and wrong.
4. What adjustments have you made to the rules you were taught?
5. Why is it that you do not lie, cheat, steal? As a child, you might have said, “because my mother told me it was wrong.” But what is your explanation now?

Doing Ethics

Ethics is the attempt to explain our morals by identifying the reason for holding certain rules or doing certain actions.² When we give reasons for our moral convictions, we are engaging in ethical analysis. Because all reasons are not equally compelling, many different ethical theories or ethical structures have been established to justify or reject a moral judgment. For example, to argue from authority (“because I said so”) is not always compelling. The argument from moral values or moral principles (“because this action respects your human dignity”) may be a stronger argument.

Ethical argument is not like debating. When we debate, we often switch sides because we know the arguments on both sides of the issue and we can step into the debate from different perspectives. But the judgments that ethics addresses are about right and wrong, good and bad. Ethical arguments have a seriousness that is often missing in debate. To lose an argument about ethics affects the deepest core of our being, our character.

For example, in the early 1990s, our nation “debated” whether or not physicians should be lawfully allowed to assist in a patient’s suicide. We who participated in the “discussion” did so knowing that our conclusions would affect not only the meaning of medicine, which heretofore had been based on the Hippocratic dictum, “Do no harm”; but also our understanding of the physician-patient relationship and the nature of the control we have over our own lives.

As we spoke our convictions, listened to one another, or read arguments from across the nation, we perceived a growing consensus, which eventually led many states to prohibit physician-assisted suicide. The lone exception is Oregon, whose legislature addressed this procedure and voted to allow the practice.

We ordinarily do ethics when we are faced with an *ethical dilemma*, that is, a situation in which our regular morals do not suffice. Perhaps it is a situation that pits two goods or values against one

another and we must choose one; perhaps it is a situation in which there is a good outcome and a bad outcome and we must justify doing something that causes harm or pain; perhaps it is a situation which calls for us to consider another way of acting that clashes with our regular code of conduct, and we don't know if we should go with the new or stay with the old.

This section will explain the use of three ethical theories: virtue ethics, principle ethics, and utilitarian ethics.³ When you use one of these ethical structures to help you frame your argument, you force yourself to think critically and speak more exactly; thus you become more effective in convincing others of your position.

Some examples of ethical argument:

I don't steal (or stealing is wrong) because

1. I'm afraid of getting caught.
2. My granddad, whom I greatly admire, never stole, and taught me never to steal. He taught me the virtue of honesty.
3. I have a duty to be honest.

Each of the three reasons why stealing is wrong differs from the others because the basis for each is different. Fear of getting caught is a possible consequence of stealing, and that fear keeps me honest. Notice how different that reason is from the one in which I use my granddad as my moral model, as the example that keeps me honest. Fear is not a motivator here. Consider, finally, when I tell you that I believe that I have a duty to behave honestly, then you know right away why I do not steal.

There are names for these three ethical theories or ethical structures:

"Stealing is wrong because I fear getting caught" is an example of *utilitarian ethics*. Utilitarianism asserts that the rightness or wrongness of an action or habit of acting depends on whether good or bad outcomes result. In this case, getting caught is a negative outcome. If a person had no fear of getting caught or any other negative consequence, then

according to this way of thinking, stealing would not be wrong. Our habits are often developed by promises of reward or threats of punishment. We hope, however, that once the habit of not stealing is engrained in us, then we will be honest, not because we fear getting caught, but for some other reason.

The second explanation, "My granddad, whom I admire more than anyone else, never stole and taught me never to do so," is an example of *virtue ethics*. This explanation does not look at the outcomes of our actions but within us at the strengths and weaknesses of our character, and the knowledge we have of persons with good moral character. Before we act, we ask, "What would they do?" When you hear someone say, "I couldn't live with myself if I pulled a stunt like that," you know that that person is using virtue ethics.

Finally, the third explanation points to a theory of principles as a justification for one's actions. When I justify an action because it is what I must do, that is, because "it is the way a reasonable person would act" or because "I have a duty to be loyal," or "honest," or "caring," I am setting forth the principle or principal values on which I rely to live a good moral life. Because we use moral values as the basis, or principles, for explaining right and wrong, we call this kind of ethical reasoning *principle ethics*.

Exercises — Using Ethical Theories to Formulate Arguments

An elderly patient lies moaning in her bed. All the medicine in the world is not enough to restore her to the woman she once was. The minister has just left her bedside and said to Cassie, the certified nurse assistant, as he made his way down the hall, "She's ready to die anytime now."

Cassie thinks, "Why should she have to wait? If she's ready, then I'll help her." And Cassie goes to her bed, places a pillow over the woman's face and presses down on it. After a few minutes, she removes the pillow, makes sure the patient is dead, and calls the director of nursing to report that a patient has died in her sleep.

Consider:

1. What moral wrongs were committed here?
2. Why do you think killing is wrong?

Possible Responses:

- because life is a precious value, and one ought not deprive another of life except under extraordinary conditions;
- because the elderly patient has a right to life and it is unjust to deny that right;
- because one can go to jail for killing a person, no matter how ready one may be to die;
- because if killing is not wrong, then someone could kill me and get by with it;
- because my parents who were loving people taught me to show respect for others and to care for them;
- because my mother, whom I dearly love, always cared for others and sent me to schools that stressed that killing is wrong.

Discussion:

The first two explanations illustrate the use of principle ethics to justify our actions; killing is wrong because it denies two values that we live by, the values of life and fairness.

The third and fourth reasons illustrate an argument from the consequences theory, or utilitarianism. We look at the consequences of an action to see how much good or bad is brought about, and we judge the action wrong because more bad comes from it than good.

The fifth and sixth reasons illustrate an argument from virtue ethics. I judge an action to be right or wrong according to how I see that action affecting my character. Or I judge an action to be wrong if someone I admired taught me it was wrong and vice versa.

Now look again at Cassie's actions. Cassie lied to her supervisor when she said the patient had just died in her sleep. Why is lying wrong?

- because truth is a value that must be upheld:

if we can't count on the word of others, our decisions will be based on misinformation;

- because if it is O.K. for Cassie to lie to her supervisor, then I can't trust Cassie not to lie to me; or
- because I do not want to be seen by my friends as a liar, but as someone whose word can be relied on.

The first argument against lying is based on a principle theory; the second, on consequences; and, the last one on a virtue theory.

Honing Your Expression — Questions for Discussion

How would you express an argument when you face the following ethical dilemmas. Identify the ethical theory you are using (e.g., principle ethics, utilitarian or consequences, or virtue ethics).

1. You see a coworker slipping a bottle of pills into her pocket as she walks past the drug cart.
2. Your supervisor asks you to team up with a coworker who is always late for work. How do you argue that you hope he or she will be on time?
3. You corrected a physician who, you thought, was making a mistake. He wants to know why you corrected him.
4. You see a coworker "coming on" to a member of the staff.
5. A patient admits to you that she is not taking her medication but enjoins you not to tell the physician.

Sometimes our reasons for preferring one action to another are intuitive and difficult to articulate, but listening actively to one another will help us recognize events that (1) threaten our values or principles, (2) have potentially disturbing consequences, or (3) test the mettle of our character. A later chapter will provide us with ways to continue educating ourselves and our committees in what it means to "do ethics."

Notes

1. Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics*. 2001. 5th ed. New York: Oxford University Press. The authors make the distinction which I have made here although others conflate “morals” and “ethics.”
2. “Adult humans *show they have a moral sense* when they strive to explain to themselves and others that what they did was morally proper. . . . The job of the ethicist is to collect these explanations and probe them for their assumed axioms [or principles]” W.L. LaCroix. 1999. *Ethical Theory*. Privately printed, 1).
3. Additional reading on the three theories that we are discussing here (consequences or utilitarianism, virtue ethics and principle ethics) can be found in Beauchamp and Childress *Principles*, and in LaCroix, *Ethical Theory*.

Chapter 2 — The Changing Face of Medicine

Bioethics as a discipline and movement came into being to address the changing face of medicine; or, more concretely stated, to empower patients to share in the increasingly complex decisions that healthcare providers must make to preserve or maintain their patients' health.

Ethics Committees, first referenced in the Karen Anne Quinlan case (1976), and called for in a report by the President's Commission for the Study of Ethics in Medicine and Biomedical and Behavioral Research (1983), were "institutionalized" by the Joint Commission on Accreditation of Hospital Operations (1992).

The JCAHO's Patients' Rights Mandate required that every accredited institution provide a mechanism for dealing with ethical conflict. Although JCAHO did not explicitly require ethics committees, committees were the response of most institutions to this mandate. Today's ethics committee members apply reasoned analysis and discourse to support clinicians, patients, and families through a vast array of clinical and organizational stress points.

From Single to Shared Decision Making

To give you a historical backdrop for your work on an ethics committee, it is well to realize that in the early practice of medicine, the physician acted as a single decision maker because it was assumed that training in the medical arts and the special experience physicians had would lead them to the right decisions. Of course, medicine was limited in what it could do; physicians could make diagnoses and prognoses, but had little in the way of active interventions. Recall, for example, the scenario of Grandma's dying that we discussed

in the introduction to this manual. Remedies were often unsuccessful and resort was often made to comfort care and to "letting nature take its course." But the driving principle was beneficence, restoring the patient to a natural state or, at least, to "do no harm."

As early as the fifth century B.C.E., the Hippocratic Oath had declared, "Whatever houses I shall visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves." But there were other codes: the Hammurabi code sanctioned "ghost surgery" and fee splitting, and the Oath of Moses Maimonides warned against "thirst for profit" and "ambition for renown."

From the beginning of medicine until World War II, the physician's practice was almost static. Nature's secrets were being plumbed and antidotes were made to some of the more noxious diseases, but three factors led to the dramatic changes we continue to experience in healthcare: technology, consumerism, and costs.

Technology

Until the 1940s, technology played no major role in the practice of medicine. That fact changed as a result of the devastation and urgency associated with World War II. Surgical advancements occurred rapidly in the 1940s. Respiratory support, namely, iron lungs, came about as a response to the polio epidemic of the 1950s; organ transplantation marked the 1960s, beginning with renal transplan-

tation and moving into multiorgan transplants; in the 1970s, attention focused on bionics, especially the artificial heart, and in the 1980s, our concern was with genetics; finally, in the 90s, artificial intelligence took to the fore.

Consumerism

At the same time, the human and civil rights movements forced medicine away from its paternalistic stance and increased emphasis on patient's rights and patient autonomy. Americans were shocked to learn of the Tuskegee experiment which began in the 1930s but which did not become known until the 1960s (and actually continued into the 1970s). To benefit research into the long-term effects of syphilis, uneducated African Americans were not told about the benefit of penicillin or offered penicillin treatments, even though its therapeutic effects were well known. Public confidence in government-sponsored healthcare research was shaken because people could not believe that their physicians would not do what was "best" for all research subjects. This incident was widely reported and is often cited as the beginning of skepticism about medicine.

In 1976, the American Hospital Association issued a Patient's Bill of Rights in which patients were guaranteed the right to be told their diagnosis, treatment, and prognosis. Patients were likewise guaranteed the right to give informed consent for any clinical procedure and the right to refuse to participate in experimentation or research. In 1990 the first so-called right-to-die case, that of Nancy Beth Cruzan, was taken by the U.S. Supreme Court which decreed that adults have a right to choose or refuse any medical or surgical treatment. And the next year, 1991, the Patient Self-Determination Act was passed by Congress which provided that healthcare organizations which are compensated by federal funds are obligated to inform patients upon admission about their right to choose or refuse any medical or surgical intervention and to make advance directives. Further, the Act requires those same organizations to provide education about these issues to staff and community.

Cost Containment

Further changes in providing healthcare were fueled by spiraling inflation in the 1970s which caused both the federal government and corporate America to reconsider commitments made to employees about healthcare coverage. These changes began with calls for better accountability and legal scrutiny. Attempts were made to control waste and fraud, fueled at least in part by the so-called Graying of America. The aging of the baby boomers created concerns about promises made to retirees and Medicare recipients.

Likewise, the 1983 capitation program introduced the now infamous diagnosis related groups, or DRGs. This maneuver made reimbursement for Medicare recipients dependent on how their treatment related to one of 468 DRGs. For example, a diagnosis of pneumonia would provide a limited amount of reimbursement; if a patient's charges were less, the provider benefited; if they were more, a special appeal could be made, or the provider would have to assume loss of revenue.

Lastly, it became acceptable to initiate discussions about rationing healthcare. In 1987, Dan Callahan, founder of the Hastings Center, published *Setting Limits: Medical Goals for an Aging Society*, in which he proposed that we have no option but to ration healthcare to the elderly. Simultaneously, it became acceptable to talk about ethics and economics in the same setting.

Thus did technology, consumerism, and cost containment become dominant factors in changing the face of medicine, and the new medical model that emerged was directly related to the organization of ethics committees. Shared decision making characterized the new model. That physicians were no longer the single decision makers also required a new vision of physician/patient relationships; and together these changes wrought a major reform in the provision of healthcare.

Shared decision making. The old paradigm of the physician as sole decision maker gave way to a new way to consider healthcare delivery. People began to realize that there are issues in healthcare

that are not just medical but multifaceted and which include concerns about law, ethics, finance, and religion, none of which can be known solely by the physician. Thus the patient emerges as a decision maker in a dyadic relationship with his or her physician.

Physician/patient relationships. From the traditionally paternalistic model to the shared model of decision making, new language arose. Physicians were characterized as technicians or engineers (emphasizing the importance technology has come to play in the practice of medicine) or as gatekeeper (stressing the place third party payors have assumed in healthcare delivery) or the physician as partner (marking the emergence of the importance of the patient in the relationship). Likewise, the terms “patient,” “consumer,” and “client” have been and continue to be used to characterize the receiver of healthcare.

No discussion of the history of the changing face of medicine is complete, however, without reference to the growing role of third party payors. Patients are controlled by corporate decisions regarding their healthcare benefits. And corporate purchasers may move large blocks of patients from one provider network to another. Long term relationships between provider and consumer have been severed; financial disincentives have forced change. The result is that many consumers have no relationship with a primary care physician.

As time passed, attempts were made to restore some of the positive benefits of more traditional physician/patient relationships, but often these were secured at the cost of higher patient co-pays. Likewise, attempts have been made to empower patients to be rational consumers, to ask questions, to examine informed consent forms, to raise expectations and question outcomes. As these steps moved forward, the value of other healthcare professionals and paraprofessionals in the field emerged.

Changes in Medicine— Questions for Discussion

1. Why was there no perceived need for ethics committees during the long history of medicine before the 1980s?

2. In view of the changing face of healthcare delivery today, why are ethics committees strengthened by having members from other specialties besides medicine?

The Emergence of Ethics Committees

As “medical ethics” shifted to “clinical ethics” or “bioethics,” three factors hastened the emergence of ethics committees: the Quinlan case, the President’s Commission, and the action of the Joint Commission on Accreditation of Hospital Operations.

Karen Ann Quinlan. The 1976 case of Karen Quinlan centered on a young woman in New Jersey who ingested a harmful mix of drugs and alcohol, suffered two fifteen-minute periods of interrupted breathing, and was left in a chronic vegetative state without cognitive functions. Her father sought appointment as her guardian along with the authority to terminate “all extraordinary medical procedures.”

The case was heard by the Supreme Court of New Jersey. During the course of the trial, the judge read an article in the Baylor Law Review which proposed that multidisciplinary commit-

tees (which the author called “ethics committees”) could be of assistance in making decisions about withholding/withdrawing life support. In the text of the Quinlan case, the judge said that if physician and family agreed and a decision to withdraw life sustaining treatment was supported by an “ethics committee,” judicial intervention should not be required. This reference marks the first time the existence of such committees was acknowledged in a legal writ.

President’s Commission. In 1983 the President’s Commission for the Study of Ethics in Medicine and Biomedical and Behavioral Research issued a report calling for hospitals to establish ethics committees to “promote effective decision making.”

Joint Commission on Accreditation of Hospital Operations. In 1988, JCAHO issued a DNR (Do Not Resuscitate) mandate that included an “ethics component.” In 1992, JCAHO’s Patients’ Rights Mandate required that every institution it accredits provide a mechanism for dealing with ethical conflict. Other accrediting agencies followed suit. Most institutions responded by establishing ethics committees, although the mandate did not specifically call for this response.

Ethics committees are intended to empower patients to participate in a shared decision-making model. They are patient centered, which is different from being patient advocates. (To advocate for the patient would assume the patient was always “right.”) Though patient centered, ethics committees provide support to clinicians and families also.

Ethics committees are not usually decision makers; however, in some jurisdictions, the courts have given ethics committees limited decision-making authority for the unbefriended, that is, for persons without family or other appropriate support. Ethics committees do provide a forum for discussion with interested parties. Indeed, their members, who have achieved some expertise in ethical reflection and argument, can provide insight, offer alternatives, question unfounded

assumptions, and offer valuable assistance to people who are searching to do the right thing.

To be effective in their advisory capacity, ethics committee members must be comfortable enough with one another to establish a culture of trust in which members will be comfortable asking for clarification and revealing their own ignorance, and one in which members can challenge one another to provide the argument for positions taken or statements made.

It has long been a custom at the Center for Practical Bioethics to invite ethics committee members to call one another by first names to level the playing field of talking ethics. Professional or social titles do not guarantee an expertise in ethics. Most people are more or less inarticulate — at best, they are halting — in expressing their ethical insights. Ethical analysis and argument is thus a habit that can be acquired only by trust, instruction, and practice.

New Members— Questions for Discussion

- 1. In your own ethics committee, what are the backgrounds of some of the members?*
 - 2. Why do you think you were asked to membership on the committee?*
 - 3. What concerns do you have about serving on an ethics committee?*
 - 4. What will be your greatest contribution to the committee?*
 - 5. What is something you will need to work on to become a better member?*
-

Chapter 3 — Educating Ourselves and Others

Education is, without question, the most important function of ethics committees. Because members will be consulted on both clinical and organizational matters, they must be knowledgeable about each. Members must first and on an on-going basis educate themselves; and then the communities they serve, both in and outside their institutions.

In a 1994 article in *Bioethics Forum*, the late David Thomasma identified five levels of education that should be of concern to members. He suggested the following activities to indicate these levels:

- updating oneself, or keeping up with, the fundamental theories and axioms of medical ethics, a study that also includes reviewing the history of medical ethics;
- developing clinical ethics skills;
- conducting ethics consults;
- developing practice guidelines from these consults that can be adopted as hospital policy by other committees and boards of the institution; and
- contributing to the institutional conscience by helping to develop a public education program.

Ethics committees should commit themselves to an educational program that will insure that at least some of their members are adept in Thomasma's five levels. Such a program will be an on-going effort to enhance members' self-knowledge so that they, in turn, can carry that knowledge to other members of the communities they serve.

Keeping Up with Fundamental Theories and Axioms

An ethics committee or its members (if the committee does not act on this matter) can choose any good ethics text to read or teach. The purpose is to learn and remind members of the committee how doing ethics "works." The select bibliography at the end of this chapter contains representative titles, but don't hesitate to ask other members of the community what kinds of readings they have found useful. Ethics, like any discipline, has its fundamental theories (e.g., utilitarianism, virtue, principle ethics) and basic starting points for discussion.

Today's committees may also look for web-based documents or websites that will fill some of their educational needs. Remember, however, that although reading is important; it is also important that you talk about the ideas you are learning or reviewing. Ask your committee to allocate time at its monthly meetings to discuss what has been read. This discussion will provide an opportunity for the committee to practice using the vocabulary of ethics.

In the same vein, a careful reading and discussion of classic court cases can be of inestimable value. Law is not ethics; yet we often find in law an expression of ethical principles. It is also possible that a court decision may be rendered though it goes far afield from a strictly ethical viewpoint. The following cases have been widely discussed

by healthcare ethicists: *Quinlan* (1976), *Conroy* (1985), *Cruzan* (1990), *Wanglie* (1991), *Baby K* (1994), *Tarasoff* (1974), and *Carder* (1987). Several of the resources included in the bibliography discuss these cases.

Developing Clinical Ethics Skills

Since the first rule of thumb in case consultations is to “know the facts,” it is incumbent on ethics committee members to know what questions to ask during a consultation and how to evaluate the answers they are given. It is certainly not necessary or desirable that committee members become “unlicensed physicians”; most of the patients and families who will seek the committee’s help will be laypeople, and nonprofessionals on the committee will be acting wisely if they discourage “either-or” thinking (which would reduce alternatives to one). They can also encourage one another to be open to a variety of explanations from life and literature. Finally they must also know when enough “facts” have been discussed to warrant moving on to recommendations.

Knowing the clinical facts is essential to the process of ethical analysis; however, facts in and of themselves never become moral conclusions (“is” never becomes “ought”).

Consider several facts about a hypothetical patient: She is 89 years old; her blood pressure is 86 over 46; her heart rate is low, and she is dehydrated. She has a discernible rattle in her chest. We cannot, from those “facts,” conclude that one ought to withdraw aggressive care. Why not? Because more than facts need to be considered: the values she lived by; the advance care directives that she made before she entered your facility; her hopes and fears about dying that she revealed to family, caregivers, and the healthcare team. Clinical data is important, but insights into her life, socially, emotionally, and spiritually, are equally — if not more — important.

Members of ethics committees who are removed from the clinical scene bear the responsibility to

become knowledgeable about the implications of clinical “facts,” and this knowledge arises most easily by asking questions: What do those figures mean? What alternatives are available that you have not mentioned? What would happen if?

Conducting Ethical Consults

Part of each ethics committee meeting should be devoted to ethics consults, either real or imaginary. Ethics is a practical science, and ethical analysis must be practiced. The steps in an ethical consult include the following basic components:

- Gather facts
- Clarify ethical issues (e.g., what values are in conflict? are there differences of opinions about the consequences of different actions?)
- Discuss “stakeholders” interests (Who has interests, and what are these interests?)
- Decide on one or more alternatives with justification for each alternative. This explanation will be presented to the one requesting the consult.
- Evaluate the outcomes.

Apply these steps to the following hypothetical case of a patient whose healthcare team requests a consult with members of your committee.

The Case of Wanting Everything for Mother

The Ethics Committee has been asked to consult on a patient who has been in our hospital for four months, the majority of time in the ICU. She is an eighty-one-year-old woman who has sustained at least eight cardiopulmonary arrests and survived each one through much medical intervention. At the time of this consultation, she is in a vegetative state, on dialysis, and vented. She has a permanent pacemaker and weighs only 65 pounds (down from 110 pounds at her peak).

Throughout her hospitalization, her chil-

dren have constantly agreed that they wanted “everything done” for their mother. Previous to this admission, the attending physician had detailed discussions with the patient concerning her wishes, and she had always stated that she wanted “everything done” even if she were on machines and had to spend the rest of her days in a nursing home. The patient had never completed an advance directive.

The neurologist and the care team agree that, at this time, the patient has little-to-no chance of any neurologic recovery. The family is aware of this information and they state that “When God is ready for her, God will take her.” The family does not speak English so all communication has been through a translator, clergy, and a family friend who is also a community member of your Ethics Committee. The care team requests the consult; they are seeking ways to tell the family that there is no medical care that they can offer the patient, including CPR and other more aggressive interventions, if she were to code. The care team is devastated at the thought of coding this frail little woman one more time.

Begin with questions of fact. Does the family understand their mother’s condition? Do they know what prompted her to ask that “everything be done”? Do they understand what toll CPR takes on frail bodies? Has the clergy person determined the theology behind the family’s insistence that “everything be done”? Has he or she attempted to discuss this theology with the family? Is the clergy person also the translator? How much of the family’s response may be influenced by feelings of cultural alienation or misunderstanding? The language barrier should be the first to fall.

Clarify the ethical issues. Apparently, a conflict has arisen between the family’s wishes that everything be done (to respect their mother and honor God’s will) and the care team’s desire not to harm the patient further (a nonmaleficence principle) and their attempt to provide proper palliative care to the patient (beneficence principle). (Further ethical values in conflict can be named.)

Identify the stakeholders. Here the major stakeholders are obviously the patient, with her previously expressed wishes, her family, and the care team who see further aggressive care as harmful to the patient’s well-being. Are there other stakeholders in the drama?

Discuss the treatment options. Think creatively. How, for example, might the family and care team respond to the idea of diminishing aggressive care rather than cutting it off entirely? Perhaps the clergy person may be able to describe such alternatives to the family to secure their agreement. Insist on the provision of intensive palliative care (often patients and their families feel that they will be abandoned if aggressive care ceases).

Offer the translator, clergy person, and family friends whatever alternatives the committee can justify and give the justification for each. Try to discover stories of similar cases within their religious group where palliation was agreed to.

Evaluating the outcome. Had this “exercise” been a real case, and if only a few members (three or four) were involved in the consult, it would be followed by a report to the full committee. Full discussion benefits all members of the committee, contributes to the committee’s education, and strengthens the committee’s ability to serve the institution by reviewing any policies that might be helpful in similar cases in the future.

After these discussions, a follow-up on the case would also be reported to the committee and an evaluation made: Were all the alternatives explored? Was the family convinced? Was “aggressive palliation” understood by the family as “doing God’s will”? Would the committee have handled the case differently if the outcome were known?

Developing Practice Guidelines from These Consults

Each ethics committee should have a case consultation procedure in writing and should frequently review it, emending it as desirable. Likewise, if case consults appear to center on a limited range of issues (e.g., end-of-life care; treatment redirec-

tion [the move from aggressive to palliative care]; or withholding/withdrawing life-sustaining treatment), the committee could review policies in place or develop new policies that would propose practice guidelines in these areas.

Contributing to, and developing, an Institutional Conscience and Public Education Program

An important role of ethics committees in health-care institutions is to offer public education about ethics to the communities served by the facility: patients and their families, staff, employees, volunteers, and even the wider civic community surrounding the institution. The educational efforts can take many forms: lectures, symposia, brown bag sessions, board retreats, and meetings with departments. Often, the most effective mechanism is to present a case and provide the audience with the framework of a case consultation (similar to our case of “Wanting Everything for Mother”). Whether the time provided is twenty minutes or an hour, a fruitful discussion can be elicited from the group and such exercises will contribute to the institutional conscience overall.

Tailor the “case” to the group, so that it deals with an ethical issue typical of their experience. If, for example, you are meeting with food service employees, use an ethical question they will recognize, such as, should staff give left-over trays to fellow employees who ask for them? If you are asked to provide a board retreat, find out some ethical issue that is of interest to the board, for example, the question whether or not to participate in a national smallpox vaccination program.

Conclusion

Ethics is both content and process. All reflective people “do” ethics, poorly or expertly, whenever they face a conflict between values or habits of conduct that lead them to rethink their moral conclusions. Education is, therefore, the primary role for institutional ethics committees. Self-education is first, foremost, and continuous, but it should be followed by educational programs for patients, families, staff, board, and employees. Ethics com-

mittees that engage in self education and outreach will develop expertise throughout their institutions. The activities of a well-organized, effective ethics committee can literally “infect” the institution with ethics.

Select Bibliography

Books and Articles

- John D. Arras, Alex John London, and Bonnie Steinbock, editors. 2002. *Ethical Issues in Modern Medicine*. New York, McGraw Hill.
- Beauchamp, Tom L., and James F. Childress. 1994. *Principles of Biomedical Ethics*, Fifth Edition. New York: Oxford University Press
- Brannigan, Michael, editor. 2004. *Cross-Cultural Bio-technology*. Lanham, MD: Rowen & Littlefield.
- Brannigan, Michael, and Judith Boss. 2001. *Healthcare Ethics in a Diverse Society*. Mountain View, CA: Mayfield Publishing Co.
- Brannigan, Michael. 2005. *Ethics across Cultures*. New York: McGraw-Hill.
- Childress, James. 1997. *Practical Reasoning in Bioethics*. Bloomington, IN: Indiana University Press.
- Jecker, Nancy S., Albert R. Jonsen, and Robert A. Pearlman, editors. 1997. *Bioethics: An Introduction to the History, Methods, and Practice*. Sudbury, MA: Jones and Bartlett, Publishers.
- Jonsen, Albert R. 2000. *A Short History of Medical Ethics*. New York: Oxford University Press.
- Kane, Rosalie A., and Arthur L. Caplan, editors. 1990. *Everyday Ethics: Resolving Dilemmas in Nursing Homes*. New York: Springer Publishing Company.
- Kelly, David F. 2004. *Contemporary Catholic Health Care Ethics*. Washington, DC: Georgetown University Press.
- Kelly, David F. 1991. *Critical Care Ethics: Treatment Decisions in American Hospitals*. Kansas City, MO: Sheed and Ward.
- Kuczewski, Mark G., and Rosa Lynn B. Pinkus. 1999. *An Ethics Casebook for Hospitals: Practical Approaches to Everyday Cases*. Washington, DC: Georgetown University Press.
- Lynn, Joanne, Janice Lynch Schuster, and Andrea Kabcenell. 2000. *Improving Care for the end of Life: A Sourcebook for Health Care Managers and Clinicians*. New York, Oxford University Press.
- Maienschein, Jane. 2004. *Whose View of Life? Embryos, Cloning and Stem Cells*. Cambridge, MA: Harvard University Press.

- Pellegrino, Edmund, and David Thomasma. 1993. *The Virtues in Medical Practice*. New York: Oxford University Press.
- Rachels, James. 2000. *The Elements of Moral Philosophy*, 4th edition. New York: McGraw Hill, Inc.
- Ross, Judith Wilson, et al. 1986. *Handbook for Hospital Ethics Committees*. American Hospital Association.
- Ross, Judith Wilson, John W. Glaser, Dorothy Rasinski-Gregory, Joan McIver Gibson, and Corrine Bayley. 1993. *Health Care Ethics Committees: The Next Generation*. American Hospital Association.
- Thomasma, David C. 1994. "Education of Ethics Committees." *Bioethics Forum* 10(4): 12-18.

Journals

Bioethics Forum, 1986-2003
CQ Cambridge Quarterly of Healthcare Ethics
Hastings Center Report
Kennedy Institute of Ethics Journal

References

- Jonsen, Albert R., Robert M. Veatch, and LeRoy Walters, editors. 1998. *Sourcebook in Bioethics: A Documentary History*. Washington, DC: Georgetown University Press.
- Reich, William Thomas, editor in chief. 1995. *Encyclopedia of Bioethics: Revised Edition*. 5 vols. New York: Simon and Schuster Macmillan.

Select Websites

Center for Practical Bioethics. You will find the Center at www.practicalbioethics.org. We offer an introduction to bioethics, a handful of case studies, and other helpful resources, and ways that you can join us for public lectures and other training opportunities. For more information about the Center and the Kansas City Area Ethics Committee Consortium, email bioethic@practicalbioethics.com. We welcome your visits, and your suggestions.

For general searches on the worldwide web. Begin with Google.com. Google processes over 250 million searches each day and delivers results within two seconds. When you type in "bioethics" in the search line, at present, the first item returned is www.bioethics.gov which is the link to the President's Council on Bioethics. Its publications are available by clicking on reports. The link to former councils and commissions will give you access to all the documents in the above-referenced "Sourcebook in Bioethics."

For in-depth research, use the **National Reference Center for Bioethics Literature** at the Kennedy Institute of Ethics and Georgetown University to plan your research topics. To get there, go to the Library and Information Services Gateway, at <http://www.georgetown.edu/research/nrchl>. As described on the site, the National Reference Center for Bioethics Literature (NRCBL), is a specialized collection of books, journals, newspaper articles, legal materials, regulations, codes, government publications, and other relevant documents concerned with issues in biomedical and professional ethics. The library holdings represent the world's largest collection related to ethical issues in medicine and biomedical research. This collection functions both as a reference library for the public and as a research resource for scholars from the United States and abroad.

The American Society for Bioethics and Humanities

(ASBH) is located at www.asbh.org. It is the professional society for persons from various disciplines who are interested in bioethics and humanities, which now numbers over 1,500 individuals, organizations, and institutions. This Web site serves as a source of information for members, prospective members, and anyone interested in bioethics and humanities.

For bioethics news, calendars of events, topical commentary, use www.bioethics.net, the home of the *American Journal of Bioethics* (AJOB). Founded in 1993, bioethics.net and AJOB have grown to become "the most read source of information about bioethics, visited millions of times every month by readers from around the world and every walk of life." It is extremely busy, looks more like a bioethics "what's in the news site" to this reviewer, but if you dig a little, it has some good offerings. Search for bioethics for beginners for example, or their tutorial on stem cell research.

American Society of Law, Medicine, and Ethics at <http://www.aslme.org>

National Institutes of Health. www.nih.gov/signs/bioethics. This website, hosted by the National Institutes of Health, has links to many university and government ethics centers in the United States and Canada, primarily, and some significant international sites as well. The webmaster annotates these links, but you really won't know what is

available on a site until you get there. Internal web pages change periodically. Therefore if you cannot locate a page trying searching for it on the home page of the host institution. The next site offers a good example.

University of Pittsburg Center for Bioethics and Health Law: <http://www.pitt.edu/~bioethic>. If you forget this address, go to www.pitt.edu, click on “search” and click on “bioethics.” This site is very useful. Rosa Lynn Pinkus is director of their Consortium Ethics Program, and they publish an online newsletter.

European Group on Ethics. http://europa.eu.int/comm/european_group_ethics/index_en.htm. Hosted by the European Group on Ethics, this site can broaden our ideas about public debate and consensus on such topics as stem cell research. It is in English.

Center for Bioethics Resources at the University of Minnesota: <http://www.bioethics.umn.edu/resources>. Has some good resources, in line with your needs; UMN helps support the Minnesota statewide network of healthcare ethics committees.

Chapter Four — Case Consultations

In chapter 3 on educating ourselves and others, we discussed the elements of a good case consultation. Ethics committees are often called on to offer insight or alternatives on how care should proceed in a specific individual case. These consults are about the ethical implications of healthcare delivery. They frequently arise in clinical practice, and have consequences for patients and their families and for providers and institutions. They may also inform our ability to make policy, thereby extending their influence beyond the individual case. For all these reasons, it is important that ethics committee members first ask for clarification about the facts related to the case. But facts are not the only consideration.

Let's take a case and walk it through a structured case review method.

Ethical Analysis — Case of Jennie M.

Jennie M., age seventy-nine, came to Happy Valley Nursing Center four years ago. At that time, she appeared to lack any decision-making capacity although she had not been declared incompetent by the court. Mary, her sixty-year-old daughter, had taken care of her until her hypertension, diabetes, and several small strokes made it impossible for Mary to do all for her mother that she had hoped to do.

When the two arrived at the nursing center, Mary handed her mother's advance directive to the admitting clerk. The directive showed that Jennie had initialed "no surgery, heart-lung resuscitation, antibiotics, dialysis, mechanical ventilator, or tube

feeding." Together they read through the directive while Jennie sat beside them, apparently not comprehending anything about the move. Mary signed the necessary papers. From that time on, she visited her mother frequently and was always cooperative when the nursing center requested information or guidance.

The years passed; Jennie began eating less and less and taking more time to consume what little she did eat. She no longer feeds herself and aides often spend over two hours feeding her to ensure that her intake meets minimal nutrition standards. The director of nursing has mentioned to Mary that consideration ought to be given to the insertion of a feeding tube. Jennie is not acutely ill; she is an elderly woman with multiple disabilities, but she is not in danger of imminent death. All she needs is sufficient nutrition, yet the director of nursing feels she cannot justify devoting so much of the aides' time to one patient three times a day.

Mary knows that her mother made her advance directive one day when a neighbor, now dead, was visiting. All that Jennie said when she handed Mary the document was "I don't want to be kept alive on a machine." Mary and the director of nursing talk about Jennie's nutritional needs, and the director mentions the use of a feeding tube. Mary says that she does not consider tube feeding a "machine," and adds that "most likely her mother did not understand the implications of initialing the statement, 'No Tube Feeding.'"

The nursing director and Mary agree, and plans are made to transfer Jennie to the nearby hospital

for the procedure. Jennie’s attending physician arranges for the transfer, but the admissions clerk sees the discrepancy between the advance directive and the request for surgery to insert the feeding tube and asks the chair of the ethics committee for advice. The chair learns the facts of the case and assembles a small subcommittee to discuss the case, requesting that Jennie not be moved until the expedited review is made. You are in that expedited case review group.

Your first task is to talk through the case. To prepare for this discussion, remember the components of case review you learned in Chapter 2. The basic components of case analysis are to

- gather the facts,
- clarify the ethical issues — what values are in conflict? are there different opinions about the consequences of various actions? —
- determine who the stakeholders are — who is an interested party? Are there multiple stakeholders, and, if so, what are their various interests? —
- consider the treatment options, including the option of redirecting treatment from curative to comfort measures; and, finally,
- decide on, and justify, one or more alternatives and present this information to the persons who called for the consultation.

These steps complete the immediate consultation. However, they must be followed by the steps necessary to evaluate the outcomes. First, let’s see how the immediate consultation unfolds, then we will see how the follow-up is conducted and how it in turns prepares the committee to do additional case consultations, education, and policy review.

Gather the Facts

In Jennie’s case, you will probably need to ask additional questions before all the facts can be known. For example, how does Mary explain her perception that “tube feeding” is not a “machine”? Can Mary tell the committee anything about the

way Jennie lived that would lead one to think that Jennie would or would not desire a feeding tube at this point? How does the physician justify his action to disregard the advance directive? Has anyone discussed with Mary the possible outcomes (i.e., rate of success) of placing a tube at this point in Jennie’s life? You can probably think of other questions similar to these. The enumeration of facts never yields a moral conclusion (the way things “are” does not necessarily lead to the way things “ought to be”), but understanding is essential to the process of determining the “right thing to do.”

Clarify the Ethical Issues

Since you are being asked to discuss the ethical issues involved in Jennie’s treatment, it is imperative that her values and principles be clearly articulated. One member of the committee might think that this case pits Jennie’s autonomy against Mary’s or against the physician’s beneficence. Both her daughter and her physician want what is best for Jennie, but if Jennie’s values are expressed in her advance directive, her values must be given precedence over the values of others, even those of her durable power of attorney for healthcare matters. Note that this way of presenting the case relies on moral principlism.

Or perhaps another of your colleagues suggests that the ethical issue here is one of presenting a course of action that provides “better” outcomes (e.g., extended length of days) or as preventing some harm (e.g., Jennie’s dying sooner). Putting the issue this way is to argue from a form of utilitarianism.

Still another colleague might express the argument this way: “If I were Jennie’s daughter, I would want my mother to have the feeding tube” or “to live as long as possible,” or “be given as much attention as she needs at every meal,” or some similar sentiment. This form of insight, called virtue ethic, leads people to put themselves in the shoes of another or to consider the issue from some personal perspective. If the analysis proceeds in this way, sufficient time must be taken to ensure

that the analogies one draws have a basis in fact, that is, in Jennie's lived experience. Otherwise, the argument fails because the comparisons are faulty.

Determine the Stakeholders

Stakeholders are all those who have an interest in the case, and when multiple stakeholders are involved your committee (or subgroup) must determine each one's interests and arrange these interests in an order of priority. For example, the physician may admit that he agrees with Mary because he lacks clarity on his own about Jennie's wishes, or he may agree with Mary because he feels she better understands her mother's desires. In both instances, committee members must make sure that the physician understands that Jennie's interests are paramount, not his or Mary's.

The effort for all stakeholders should be on getting to the meaning behind Jennie's cryptic remark, "I don't want to be kept alive on machines." Mary is an important stakeholder here; she has been caring for her mother with great skill and compassion. Nevertheless, discussion with Mary should be directed to understanding what Jennie wants, not what Mary wants for her mother.

As Jennie's values are primary, Mary should be encouraged during this part of the conversation to talk to friends of her mother's, or members of the clergy (if appropriate), so that she can truly focus on what is best for her mother.

Discuss Treatment Options

Treatment options in this case are fairly straightforward. They include increased efforts to feed Jennie, acceding to Mary's desires to have a feeding tube inserted, or honoring Jennie's advance directive for "no tube feeding." The first and third of these options are very similar. A fourth alternative is also possible: accede to Mary's request to place a feeding tube but with a time trial to reconsider the issue after a certain length of time, for example, in two to four weeks. Withdrawing life sustaining

treatment because it does not fulfill the reasons for using it in the first place is morally defensible and right.

Decide and Justify the Alternatives

Decide which treatment option or options should be presented and provide the justification and give it to Mary and her physician in oral or written form. Remember that the recommendations of ethics committees, though they carry moral weight, do not in themselves constitute an edict for action. You were asked for your consideration; you do the best you can; you pass on your recommendations. The analysis is done, but you are not yet finished.

Outcomes – Evaluate the Case

When the expedited review group meets again with the full ethics committee, it is incumbent on the participants to share the experience, the questions probed, the alternatives offered, and the insights gained. In this way, every member of the committee participates in the case consultation and follow-up can be requested. The full committee evaluates the outcomes of the case review.

In the full committee, as in the expedited review, you must be attuned to the ethical structures within which each person expresses his or her arguments. One does not argue effectively if one cannot get inside the structure being argued against.

Identify the Ethical Theories

Think back to section one where you were introduced to three ethical theories or ethical structures: utilitarianism, virtue ethics, and principle ethics. Each theory will emphasize different questions and the different weight given to one kind of answer over another. For example, utilitarianism will place more emphasis on the consequences of an action than will virtue or principle ethical thinking. You will find yourself asking, "What will happen if we act in such a way to Jennie?"

Those using a principle ethics will ask at the outset, “What values are we pursuing in our treatment of Jennie?” while those using a virtue ethics will inquire, “Would I want this treatment for my loved one?” If we argue a form of Utilitarianism, we make our reflections from the point of view of the consequences (positive and negative) of placing a feeding tube in Jennie.

Utilitarianism. Person A says: I argue that the tube should be placed because without it, Jennie will die. Jennie never gave explicit instructions so we can assume we are doing what is in her best interest. If we don’t do it, Mary will think she — and we — are killing her mother.

However, Person B responds: I disagree. The result of putting in the feeding tube will only postpone Jennie’s death a little. Jennie is old and tired and her whole system is wearing out. Jennie marked “No Tube Feeding.” You can’t tell me that she didn’t understand the consequences of that option.

Jennie knew that she would be entering her last days if tube feeding were being discussed, and she wanted her daughter to know that “When it’s time to go, I want to go.” Mary will think that not putting in the feeding tube is the right thing to do if we explain about Jennie’s condition and the limited success rates feeding tubes have in people like Jennie. Why don’t we explain to the daughter the consequences of inserting a feeding tube and see if Mary still wants her mother to go through with that?

Notice how the major point in utilitarian arguments, pro and con, is to ascertain the *consequences* of one’s actions, which, in this case, is to insert or not insert a feeding tube.

Principle Ethics. Suppose, however, that we approach the argument differently. The tenor of the argument, pro and con, will change from consequences to moral principles and values. For example, we may argue for an alternative based on “Do no harm” or based on “patient autonomy”

but notice, again, that arguments from principles and values can be for or against inserting the feeding tube.

Person A says: I think we should place the feeding tube because not to do so would mean that Jennie will suffer. I believe, as our healthcare code states, that we should “Do no harm,” and we will be causing harm to Jennie if she has to starve to death. Besides, if Mary instructs us to insert the feeding tube, we shall be honoring Jennie’s autonomy because Jennie named Mary as her durable power of attorney for healthcare decisions. Listening to Mary is the same as listening to Jennie.

Person B responds: I disagree with your interpretation of “Do no harm.” I think to insert a feeding tube in Jennie will harm her because you are not treating her with respect. You are, in effect, violating her autonomy. She deliberately asked that she not be kept alive, and here you are, considering doing just that. Isn’t that what the law calls “battery”?

Person C agrees with B, saying: Yes, our argument is that Mary does not really understand what Jennie meant, and therefore is not acting for Jennie’s welfare. Mary means well, but she does not understand that tube feeding can be intrusive, even painful, if Jennie’s body is shutting down. Jennie’s desire “not to be kept alive on machines” expresses far more than a simple discussion about feeding tubes and I am not sure Mary is open to that discussion.

Virtue Ethics. Still others on the committee may analyze the case using a virtue ethics. Again, the tenor of the argument will change. Virtue ethics concentrates on character, on what it means to be a good human being, a good mother or father, a good child. Anytime you have ever said, “I couldn’t face myself in the mirror the next day if I did thus and so,” you are using a virtue ethics. You are not referring necessarily to the consequences of an action as the source of its moral standing; nor are you thinking of the values the act will enhance or

the principles that will be served. You are looking at your own character, and how it will be affected by acting in one way or another.

Person A makes the case using virtue ethics: I think we should insert the feeding tube because if the tables were turned, I'm sure Jennie would make that decision for Mary. Jennie has been good to Mary, and she must follow her own lights as a daughter to figure out the best thing to do for her now. I know this by thinking about how my mother and I would act in this case.

Person B uses a virtue ethic to make the opposite decision. He says: I insist that you not insert the feeding tube. My mother has been so good to me all my life and she reared me to be strong when making tough decisions. And this is a tough decision, but the good thing to do here, the resolution I can make as a good daughter, is to let my mother die. Do not postpone the inevitable decision any longer. She is worn out, she is tired, and she wants to have it over. I'm sure Mary wants to be a good daughter, and make the tough decisions her Mother has reared her to make.

As a member of the ethics committee, what are you to make of this exercise? Your awareness that arguments can be differently crafted while using the same theory or structure (utilitarianism, principlism or virtue ethics) will help you have patience and respect for the process of case consultation and review. Sometimes, the argument will not be resolved, and we must simply agree to disagree. But as we listen to others frame their positions, we are often swayed by the reasonableness of the position they take, so much so that we assume that position ourselves. At other times, your argument will compel the assent of the others.

Going Deeper

It is important for us to recognize the position taken by another so we can respond in the same vein. A utilitarian argument should be supported by, or countered with, a utilitarian argument. If someone is thinking about consequences, results, and outcomes, and another begins speaking about

moral values or a person's character, you may see a glaze of misunderstanding pass over the other's face. It is almost as though an interpreter is needed between two persons speaking different languages. Unless we can place ourselves within the other's frame of reference, we risk incomprehension, and charges of "you simply don't understand!" If we know the framework of the other's reference, we may be able to meet him or her on a level playing field.

So how do we accomplish this meeting of minds and hearts? When an ethics committee consults on, or reviews, a case, we must be wary of thinking about the consultation as a debate. It is not a disinterested or merely intellectual give and take. Because a moral issue is at stake (i.e., the right thing to do), the entire tenor of the argument changes character. If, as a participant, you are at sea regarding your own position on the case, admit it frankly. Say something like, "I don't know where I stand on this case, but I would like to take a position and then hear your opposing arguments."

On the other hand, if you have a clear position, then make the best argument you can marshal. But conduct the discussion with civility. It is not always easy for people to buy into our moral insights. Perhaps they have been reared differently, according to a different moral code or with a different priority of values; perhaps they sincerely cannot see or agree with the argument we are making. That's the purpose of having time to present your arguments cogently.

Recall the point we made previously, namely, that it is off the mark to counter a utilitarian argument with an argument from another perspective. Suppose, for example, that you say that Jennie ought not to have a feeding tube placed because statistics indicate that tube feeding in people like Jennie has few benefits; that is, that pain, discomfort, and failure to meet long-term treatment goals, among other poor outcomes, militate against the insertion.

Suppose, further, that another committee member replies, "But aren't you starving her to

death?” This question has introduced a totally different argument: your argument was based on utilitarian thinking; the second one is based on a principles ethic or a virtue perspective. Starving someone to death can never be justified no matter how many good consequences you bring to the argument. In this example, while you are arguing burden and benefit, the other person has introduced an entirely different reference point.

Make clear that the point about starvation needs to be addressed and that you will postpone making your utilitarian argument while you address this point. Or you can say, “Stay with me as I develop my utilitarian argument for a time and I promise to address what you are calling *starvation*.”

In examples like Jennie’s, withholding life-sustaining food and hydration need not be “starving” a person; often in our dying, our bodily functions shut down and forced feeding can be painful and counterproductive. One “starves” another who can benefit from food. If Jennie is in the dying process, there will be no benefit gained. She should be made comfortable and palliative measures should be liberally supplied.

Remember that as an ethics committee member, you are making recommendations to patients, families, healthcare professionals — to whomever asked for your help. Sometimes those recommendations will be the result of consensus; at other

times a minority report will be needed from those who cannot, in conscience, agree with the majority. The committee’s recommendations inform the decision makers, and sometimes it is enlightening to know that the ethics committee could not agree on “the right way” to act.

Case review often alerts the wise committee member of the need to hone one’s skills in argument and argument recognition. But one also needs to keep abreast of facts and of appropriate legal cases especially if the judgment gives the ethical and legal foundations for the decision.

Questions for Discussion

Consider a case from a past issue of *Bioethics Forum* or *Practical Bioethics*. Following the procedure outlined in this chapter, gather the facts and clarify the ethical issues. Identify the ethical position you are adopting, and the recommendations you would make to the parties consulting you in the case.

If you have the opportunity to engage your ethics committee or some members of the committee in this exercise, then before adjourning the discussion, ask the group how they would document this consultation.

Case Studies are also available from the Center’s website. Go to www.practicalbioethics.org and click on case studies.

Chapter Five — Policy Review and Development

Ethics committees have the moral authority to initiate and review policy and the ability to work with others in their policy considerations. Accrediting agencies often inquire, for example, if patients' rights' policies have been reviewed by ethics committees. They assume that ethics committee members have knowledge about how healthcare delivery works and insight into how it ought to work to enhance human dignity rather than demean it. Policy review and development can take a tremendous amount of time, but it is a major factor in changing behavior within an institution.

Writing a Policy

Are there indicators when a new policy is needed? Imagine the following scenario: Several case consultations have been called to discuss requests by family and friends about withholding or withdrawing life-sustaining treatments. Each of the consults has addressed a unique situation in relation to this class of treatments, but it is becoming obvious that a hospitalwide policy is necessary.

When a member of the ethics committee or the chair raises the need for such a policy, a sequence of actions follows. First, the entire committee should meet and discuss the problem. The problem should be identified and its ethical implications explored. Decide what actions are to be promoted or amended, and list specific objectives. Precisely what needs to change in our experience and what

are the evaluation criteria that we will use to determine if our objectives have been reached?

Following these initial discussions, the committee can generate a list of working assumptions; for example, that "patients with decisional capacity have the moral and constitutional right to make decisions about continuing, limiting, or removing life-sustaining treatment."

Next, the chair of the committee should assign a subcommittee to draft the new policy. Do not have the committee as a whole write the policy.

Policies should have five basic components, including the following:

- statement of the policy,
- a statement of the ethical principles underlying the policy,
- definitions,
- procedures, and
- implementation and evaluation.

In general, policies should be as brief as possible. A fifteen-page policy equals no policy because no one will read it.

Statement of the Policy

Summarize the topic of the policy as it applies generally and any major exceptions that might apply. Thus, for example, you may have a policy that states: "Advance directives will be honored when patients are without decisional capacity."

Statement of Ethical Principles

Clarify the foundational principles or values that underlie the policy. The institution's mission statement provides a rich resource for determining the institution's publicly held values, and its history and traditions are another rich source. The moral principles most often referred to in healthcare are autonomy, beneficence (or nonmaleficence), truth telling, promise keeping, and justice.

Institutions sponsored by religious groups may state principles in theological terms. Secular institutions may use more philosophical language, but neither should make the principles or values sound so "lofty" as to appear unreal. Consider the following policy:

"Patients with decisional capacity may refuse any medical or surgical intervention so long as they understand the implications of their choice and the possibility of any other treatment." This policy in a religious setting may be supported by language referring to the value of "freedom of the will." In a secular environment, policymakers may refer to "autonomy" to express their respect for a patient's right to decide.

Definitions

In formulating policy, all ambiguous terms must be clearly defined so that interpretation of the policy does not lead to substantially varying or unintended results. Commonly undefined or ambiguous words in the clinical milieu include

- terminal illness,
- imminent death,
- advance directive,
- family,
- surrogate,
- decisional capacity,
- medically indicated,
- invasive procedure,
- informed consent, and
- futile treatment.

Here, for example, is a definition for *advance directive*:

an advance directive is any directive, either written or oral, made in advance of losing capacity by an individual regarding his or her healthcare treatment wishes.

Written advance directives may include living wills, healthcare treatment directives, and durable powers of attorney for health care. Notice that both oral and written instructions are included in this definition as well as other samples of advance care planning.

Procedures or Guidelines

Policy "wonks" like to discuss whether policies and procedures should be incorporated into one document. Anything that makes this information more accessible to clinicians is helpful. Therefore, we recommend keeping them together.

Write down the specific, pragmatic steps that need to be taken to implement the policy. Such steps may include guidance about how the policy should be recorded in the chart, who is to be consulted in the event of disagreement, and who is to be informed in the event of certain actions.

Verbs are very important in policies and procedures. "May," "ought" or "should" is used when direction is advisory. "Must," "will" or "shall" is appropriate when direction is mandatory. Thus it is immediately clear from the following statement that a gold sticker on the front of a patient's chart if he or she has an advance directive is not optional:

A gold advance directive sticker *must* be placed on the outside of medical charts for all patients who have advance directives.

When developing a policy, a subcommittee of the ethics committee should seek input from others. They must circulate the clearly marked draft proposal throughout the hospital and encourage responses to the draft. Identify the "stakeholders" in the hospital who would be especially affected and make sure that copies of the draft are available

to them; take the proposal to the medical staff to secure their support for the policy; have your legal counsel review your on-going efforts and the final statement. Throughout the process, avoid pressing timetables.

Implementation and Evaluation

Finally, secure approval for the new policy through all the appropriate channels, making sure that all healthcare providers and others affected by the policy know about it. See that it is published in the appropriate manuals, presented clearly at department meetings, and posted on bulletin boards wherever it is relevant. The new policy should also be discussed at orientation sessions for new staff.

Continue to monitor, evaluate, and revise the policy. Hold focus group meetings to consider if revisions are in order and send out surveys with questions that target the policy or parts of the policy that appear in need of review. Audit patient charts, if possible, to see the impact of the policy and its procedures on patient care.

Reviewing a Policy

The steps you follow in developing a new policy will help you conduct policy reviews. Discuss the same criteria this time in question form.

1. Is your statement of the policy clear and concise?
2. Are the ethical principles expressed clearly? If not, how can they best be articulated?
3. Are the requisite definitions attached to the document?
4. Have you determined that proper procedures are in place to effect the policy?
6. Was your implementation plan and evaluation measures clearly stated (and properly carried out)?

Practicing Policy Review — An Exercise

Turn now to the document beginning on page 33. It is a guidelines document for a policy on “Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment” that was developed by the Kansas City Regional Ethics Committee Consortium. We will use this document to practice policy development and review.

First, read through the entire document carefully, noting the prologue, the purpose, rationale, and goals of the policy, and the problem or needs that the policy was intended to address.

Then review the definitions and principles or values that served the group. Note too, the assumptions that served as common ground for those preparing the guidelines on withholding/withdrawing life sustaining treatment.

Next, investigate the policy itself — the general guidelines for decision making in matters regarding withholding or withdrawing life-sustaining treatment lays out both policy and procedures.

Finally, review the measures suggested for monitoring, evaluating, and documenting decisions made according to this policy.

Once you are familiar with this document, compare your hospital’s policy on withholding/withdrawing life sustaining treatment. Perhaps your policy is not so detailed, but in reviewing it, you ought to be able to identify the components that we have presented here, even if they are not explicitly expressed.

If you cannot find the correlations between your policy and this one, how would you work on a reformulation? With whom would you work?

Policy development and review may not be the most glamorous task the ethics committee will be asked to perform, but its importance will be immediately evident and satisfying to those who accept the challenge.

Tips for Policymakers

When you are serving on a subcommittee to review a policy, or if your entire committee must review or develop a policy, remember to focus your interest on statements of the policy and principles, definitions, values and how the policy is implemented and evaluated.

- You should expect to be told why the policy is under consideration or what issues make the policy necessary.

If someone answers your question, “Because JCAHO told us we have to have it,” you can respond: “Why do you think the accrediting agency did that?” Your question will elevate the discussion from a compliance to an ethical level.

- You will also serve a useful purpose if you read the policy from a layperson’s point of view.

Can a nonprofessional understand the meaning of the terms used? If the answer is uncertain, then ask for commonly understood definitions.

- You will be acting as a responsible ethics committee member if you also ask for the principles or values on which the policy is, or will be, based.
- If the text does not clearly infer the basis on which the policy rests, that basis must be supplied.

It sometimes happens that the moral principles that underpin a policy are obvious to the writer but not obvious to other persons throughout the institution.

- Your responsibility also includes helping the committee determine if the gist of the policy can be clearly grasped at a first reading.

Additional discussion may be necessary to find the clearest language and ensure that the specific steps whereby the policy can be implemented, reviewed, and revised are clearly stated.

Asking for clarification ahead of time is appropriate and can save a ton of misunderstanding later.

Your responsibility as an ethics committee member is to raise questions, seek clarification, and, if necessary, call for revision.

Considerations Regarding Withholding/ Withdrawing Life-Sustaining Treatment

Kansas City Area Ethics Committee Consortium of the Center for Practical Bioethics

Remember

Your responsibility as an ethics committee member is to raise questions, seek clarification, and, if necessary, call for revision.

Prologue

Members of the Ethics Committee Consortium believe that these considerations for forgoing life-sustaining treatments will benefit ethics committees as they review cases, develop educational programs, and assist in the development of policies within their institutions. These suggestions are intended to assist hospital ethics committees, palliative care consultation services, family caregivers, healthcare providers, and others. It is important to note also that Consortium members do not believe that this list is comprehensive. It is not the goal of the Consortium to develop a model policy or a community standard.

I. Purpose/Rationale/Goals

- A. Provide practical guidance to consortium members, their ethics committees, palliative care consultation services, risk managers, and others about ethical issues related to withholding/withdrawing life-sustaining treatment.
- B. Provide support to healthcare providers who believe withholding/withdrawing life

sustaining treatment is the most appropriate treatment option.

- C. Establish a coherent philosophical/ethical foundation to help ethics committees become more effective when providing case consultation involving withholding/withdrawing life-sustaining treatment.
 - D. Empower institutions to facilitate appropriate discussion of withholding/withdrawing life-sustaining treatment.
 - E. Establish decision-making procedures based on systematic, rational, ethically defensible considerations.
- ### II. Problem/Needs to be Addressed
- A. Increased technological capacity to sustain life has created the need for critical examination of circumstances in which such treatment may be inappropriate.
 - B. Providers must respect the critical role that patients and families play in healthcare decision making.

- C. The decision to forgo life-sustaining treatment poses significant psychological difficulties for providers, patients, and families.
- D. Although medical boards, legal associations, and many other thought leaders support patient choice, the legal system continues to be drawn into withholding/withdrawing treatment decisions. Many providers and families are reluctant to make decisions that reflect the patient's choice because of perceived legal risks.
- E. Inequalities in the availability of healthcare raise concerns about the inappropriate use of scarce resources.
- F. Due to the aging population, and more assertive patients, providers are confronted with an increasing number of cases involving forgoing life-sustaining treatment.
- G. Various studies indicate that even when an ongoing provider-patient relationship exists, providers are hesitant to discuss end-of-life issues with patients and their families and often do not know the patients values and goals.
- H. Within and between institutions there are diverse practices regarding withholding/withdrawing life-sustaining treatment. Regulatory agencies will increasingly require providers to develop policies and procedures regarding these decisions.
- I. Court decisions in some states have given healthcare providers cause for concern about the potential for legal problems should they withdraw artificially administered nutrition and hydration from a patient without capacity.
- J. Healthcare providers are being asked to provide treatments which they believe to be ethically inappropriate and without benefit to persons who lack decision-making capacity.

III. Definitions

- A. Best Interest decisions — the method used by surrogate decision makers to determine what is best for a patient whose preferences are not known; a decision based on what reasonable persons would choose under similar circumstances.
- B. Decisional capacity — the ability of a patient to make a specific decision; that is, the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) decisions or preferences to providers.
- C. Family — a relative or intimate friend.
- D. Futile — a treatment determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient's well-being or of achieving agreed-on goals of care.
- E. Life-sustaining treatment — interventions that are judged likely to be effective in prolonging bodily functions.
- F. Palliative care — a range of treatments intended to provide relief of pain and/or suffering, control symptoms, reduce anxiety, and provide comprehensive support to patients. Such care is sometimes referred to as "comfort" care — care that serves to relieve or alleviate pain and suffering without attempting to cure.
- G. Persistent vegetative state — a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.
- H. Substituted judgment: the method used by surrogate decision makers who know the patient well enough to determine what he or she would decide; a decision by a surrogate based on the expressed preferences of the patient.

- I. Surrogate — an agent or agents who act on behalf of a person who lacks capacity to participate in a particular decision. An appropriate surrogate may be: (1) identified by the patient (e.g., in a healthcare treatment directive, living will, or durable power of attorney); (2) appointed by a court (e.g., a guardian); or (3) the adult who is most involved with the patient and most knowledgeable about the patient’s personal values and preferences.
- J. Terminal Illness — an illness, which because of its nature, can be expected to cause the patient to die, usually within six months; an irreversible and unrelenting condition for which there is no known cure.

IV. Identification of Principles

All persons, regardless of their diagnosis or condition (including their medical, ethnic, social, religious, and financial condition) have intrinsic value and personal dignity and deserve compassion

A. The principle of respect for autonomy

Patients have the right to be self-ordering and to make treatment decisions that will affect the course of their lives. This is often called the patient’s right of self-determination or autonomy. Important aspects of autonomy include the concept of informed consent; the presumption that patients have the capacity to make decisions and the right to delegate decision-making authority; the patient’s right to be adequately informed; and, the right to authorize or refuse any medical treatment.

B. The principle of beneficence/nonmaleficence

The obligation to promote the good of the patient is basic to the relationship of healthcare professionals and patients. The obligation to promote the patient’s

good involves identifying the possible benefits and burdens from the patient’s perspective

One of the oldest and most established principles of healthcare ethics counsels providers to avoid or minimize any harm to patients. Providers are obligated to carefully weigh the burdens and risks associated with any proposed treatment. When treatment becomes unacceptably burdensome to the patient, no longer provides reasonable benefits to the patient, or is inconsistent with the patient’s known wishes or goals of treatment, it should be discontinued.

C. The principle of justice

Decisions about life-sustaining treatment should be based on clinical judgment and the patient’s known goals and wishes, not on considerations of race, ethnicity, or socioeconomic status. Simply stated, like cases should be treated similarly.

V. Assumptions Regarding Decisions to Withhold/Withdraw Life-Sustaining Treatment

- A. A patient’s decision to forgo life-sustaining treatment does not constitute a decision to commit suicide. Death occurs as a result of the patient’s underlying condition.
- B. A healthcare provider’s decision to respect the patient’s or surrogate’s wishes to withdraw or withhold life-sustaining treatment does not constitute killing or euthanasia.
- C. Healthcare providers have an obligation to provide treatment and care that will allow a peaceful and dignified death with minimal suffering.
- D. The assumption that patients and families want to prolong life in every circumstance provides inadequate guidance to healthcare providers.

- E. Healthcare providers and/or institutions that object to a decision to forgo treatment should inform the patient or surrogate of their position and assist in the orderly transfer of care to another provider or institution. Institutions that have policies that limit patients' choices should make those policies known to patients on or before their time of admission.
- F. All life-sustaining treatment, including, for example, artificial nutrition and hydration, may be withheld or withdrawn. If doubt exists regarding possible benefits or burdens of a treatment, time-limited trials of treatment may be helpful and should be undertaken with the clear understanding that ineffective treatments can be stopped.
- G. When a decision to forgo a particular life-sustaining treatment is made, both healthcare providers and the institution have a continuing obligation to provide palliative care.
- H. Providers usually have the obligation to respect patients' (or patients' surrogates') requests to be provided with, and continue to receive, life-prolonging treatment. However, providers are not obligated to provide treatments that are clearly futile; nor are they obligated to provide treatment if in their judgment it is ethically inappropriate. If conflict occurs, providers are obligated to engage in conflict resolution. If the conflict cannot be resolved, they are obligated to assist in the orderly transfer of the patient to another physician.
- I. That a therapy has been initiated as part of an experimental protocol or because of complications of medical treatment should be irrelevant in a withholding or withdrawing treatment decision.

VI. General Guidelines for Decision Making

A. Model of Shared Decision Making

These guidelines presume that the ideal model for making treatment decisions is one in which the responsibility is shared by providers and patients or surrogates although, when known, the goals and values of the patient are given special consideration and are always at the center of decision making. Members of the health-care team and the patient or surrogate should have an opportunity to participate actively in all such decisions. When there are conflicting judgments regarding the appropriateness of a decision, mechanisms such as ethics committee consultations or palliative care consults should be available to address and help resolve such conflict.

B. Sound Ethical Decision-Making Criteria

Clinical decision making is a complex process. No simple formulas or rules will suffice; however, there are parameters about which there is general consensus. Used with knowledge and experience, these parameters provide guidance about how to make an ethical treatment decision.

1. Persons with decisional capacity may choose to forgo any medical or surgical intervention.
2. Surrogate decision making for persons without decisional capacity:
 - a. Substituted judgment decisions: If the providers and surrogate determine that forgoing life-sustaining treatment is clearly in accord with the patient's values and previously expressed preferences, that plan of care should be pursued.
 - b. Best interest decisions: When the wishes and values of the patient are not clearly known or discernible,

the providers and surrogate cannot determine that forgoing life-sustaining treatment is in accord with the patient's values and preferences. In such cases, decisions should be based on the patient's best interest. Best interest can be defined as the choice that reasonable persons would make for themselves if they were in the patient's condition. In applying this standard:

- To patients who are terminally ill, the major considerations are to avoid the burden of prolonging dying and to determine whether the patient has the potential to achieve some satisfaction from prolonged life.
- To patients who have a severe and irreversible illness, the decision should be made by balancing the benefits and burdens in each case.

In all cases involving the best interest standard, an ethics consultation may be helpful.

3. No simple formula will capture the complexities involved in determining who among the patient's friends and relatives is or are the appropriate surrogates if no one has been designated by the patient. The responsibility is, therefore, on the physician, with the assistance of the ethics committee, to identify a surrogate who is well acquainted with the patient and willing to assume this role.
4. In situations where no surrogate can be found who is well acquainted with the patient and willing to assume this role, an ethics committee may be helpful to the provider. The provider in consultation with others (e.g., nursing home staff, ethics committee members) should be comfortable making decisions about

withholding or withdrawing treatment without involving the court. Seeking a court-appointed guardian should be considered a matter of last resort.

C. Role of the Healthcare Provider

Providers have a responsibility to advocate for the welfare of their patients. This responsibility will ensure that decisions to forgo life-sustaining treatment are patient focused and complemented by palliative care, and that concerns about cost and malpractice do not become the grounds for decision making. The provider's responsibility includes ensuring that

- a comprehensive and accurate evaluation of the patient's condition has taken place;
- the entire range of treatment options has been carefully considered;
- time-limited therapies have been conducted as appropriate;
- palliative care has been included in the treatment plan;
- the appropriate surrogate has been determined; and that
- the patient or surrogate is informed and involved in the process.

D. Futile Treatment

Futile treatment is any therapeutic act or course of action determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient's well being or helping to achieve the agreed on goals of care.

1. If the care providers directly involved in the care of the patient agree that a treatment is futile, there is no ethical obligation to provide the treatment.

2. A patient or the patient's surrogate should be fully informed when a treatment that could be used, such as CPR, is considered futile.
3. If a patient, the patient's surrogate, or physician requests a futile treatment, all options should be explored for resolving the conflict, including an ethics committee consultation. If the conflict cannot be resolved, the provider may withdraw from the case and transfer care to another physician. Although the provider has no ethical obligation to provide futile treatment, he or she is morally obligated not to abandon the patient.
4. Involving the court in conflicts related to medical futility should always be a last resort.

E. Role of the Patient or Surrogate Decision Maker

1. Patients with decisional capacity: The decision by a patient with decisional capacity to forgo a potentially life-sustaining intervention is attested by the patient's informed consent. Adults with decisional capacity, even when not terminally ill, have the right to refuse to authorize any medical or surgical intervention.
2. Patients who have made their wishes known: If a patient who lacks decisional capacity has previously executed an advance directive or otherwise made known his or her preference that a life-sustaining treatment be withheld or withdrawn, such directions should be respected. Where a patient has appointed a surrogate to make such decisions (i.e., a "durable power of attorney" or "healthcare surrogate"), decisions made by the surrogate should be honored.

Surrogate decisions can always be challenged on the basis that the surrogate is not acting consistently with the expressed preferences and values of the patient. As surrogates are obligated to act in accord with the patient's expressed wishes, the surrogate who is not following the patient's expressed wishes must be able to provide the basis for the decision. An ethics committee consultation may be appropriate in these circumstances.

3. Patients with prior decisional capacity who have not executed an advance directive or appointed a surrogate: Where possible, providers of such patients should work with the patient's family and appropriate others to identify an appropriate surrogate decision maker: one who knows the patient's values and preferences. If the patient has been declared legally incompetent, the surrogate would usually, but not always, be the court appointed guardian.
4. Patients who lack decisional capacity, are unbefriended, or who never developed decisional capacity: When decisions to forgo life-sustaining treatment involve a person who has never developed decisional capacity, such as infants, young children, or persons with severe mental impairment, or unbefriended persons, it is not possible to base such decisions on the individual's preferences and values. Surrogate decision making in these circumstances will be based on the best interest standard.

F. Role of the Institution and the Ethics Committee

1. The primary duty of the healthcare institution is the care of patients, including supporting those patients and families who face decisions about withholding and withdrawing treatment. The insti-

tution can fulfill its responsibilities to these persons through a wide range of mechanisms, including ethics consultation, case management conferences, mental health or pastoral counseling, palliative care consultation, and review by the institutional ethics committee.

2. The primary responsibilities of the ethics committee are advocacy, case consultation, and policy review and development.
 - a. The primary role of the ethics committee is to advocate for the patient.
 - b. The ethics committee will provide a forum in which questions and/or disagreements regarding decisions to forgo life-sustaining treatment can be discussed and recommendations made.
 - c. Committee consultation and review may occur in response to a request from a patient, the patient's family or surrogate, or from any provider directly involved in the patient's care.
 - d. Such consultation is strongly recommended for cases in which an appropriate surrogate has not been

found for a patient lacking decisional capacity, and in cases in which there is persistent disagreement among those responsible for making the decision.

3. Legal resolution should be an option of last resort.

VII. Changing the Decision

All parties in decisions to forgo life-sustaining treatment should be aware that such decisions can be changed at any time if desired by the patient or if a reassessment or change in the condition of the patient warrants such a change.

VIII. Documentation

- A. Discussions and decisions regarding the withholding or withdrawing of life-sustaining medical treatment should be documented in the medical record. Documentation should include the basis of the decisions, and a record of the process by which the decisions were made.
- B. When an ethics committee consultation regarding withholding or withdrawing treatment has occurred, that fact should be noted in the medical record in addition to the ethics committee's own documentation of the consultation.

For additional copies of this policy guideline or for other model guidelines of interest to hospital ethics committees, contact the Center for Practical Bioethics. *Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment* was last updated by the Kansas City Area Ethics Committee Consortium in 2005. ©Center for Practical Bioethics. All rights reserved. Please send your queries to bioethic@practicalbioethics.org, call 816.221.1100, or visit the Center at www.practicalbioethics.org.

Conclusion

Where We Have Been and Where We Are Going

Where We Have Been

From the beginning of the resurgence of ethics committees in the early 1980s to the affirmation of their important role by the Joint Commission in the 1990s, despite the vast amount of time and talent invested in them, it appears that they have not lived up to their potential. It is true that, as a direct result of their efforts, much education has been offered in institutions where they are active, more and more policies have been reviewed, strengthened and/or developed because of ethics committees' oversight, and across the nation case consultations in the thousands have taken place which, hopefully, helped those who requested them.

Even with the added responsibility of doing organizational ethics, which some but not all ethics committees embraced, the potential for creating a real difference in the institution was deemed unfulfilled. Although we have successfully created multidisciplinary committees, we have not overall insisted on board involvement; thus when real change happened because of board action, we felt left out of the loop.

History also was working directly against us: the chaos of healthcare delivery nationwide has resulted in 65 million Americans un- or underinsured, 22 percent of the population. We deemed ourselves helpless in this rampant tide. Like-

wise, more and more healthcare professionals found themselves caught in a spiral of lowered self-esteem and hospitals experienced patients who entered their doors expecting to be treated badly because of the negative media reporting. Had ethics committees exercised more advocacy instead of insulating themselves from the hurly-burly of healthcare delivery, perhaps the tide could have been stemmed; perhaps not.

The fact remains that we have across the nation well-educated, highly trained professionals who are eager to "do" ethics as a resource in their institutions. They have much to offer for educational outreach, policy review/development, case consultation, and often, for institutional or organizational ethics issues. Perhaps their greatest weakness is that they did not trumpet their own expertise. Had the existence of ethics committees been "marketed" like palliative care services or heart institutes, their history might be different today

Where We Are Going

The skills learned and exercised over the past thirty years will serve as a sound foundation to the future of ethics committees. "Doing ethics" remains a philosophical art, developed by practice, and exercised on multitudinous issues. But the future of ethics committees will probably be marked by the following changes:

- Ethics committees will be more intent on assessing their performance than they formerly were. In the past, “talking” ethics was often equated with “doing” ethics, so meeting times could be spent in speculation and reflection, often with no discernible practical outcome. Future ethics committees will be increasingly aware of the need to prove their accountability to board and administration.
- There will be less concentration on the individual and more emphasis placed on the organization or the system. That is not to say that case consults involving a particular patient or family will no longer be required, but it will be the norm that individual consults will result in the need to address institution-wide (or systemic) implications of the problems that

necessitated the consults.

- Finally, ethics committees will cast off their insularity and embrace joint ventures with other groups whose concern is quality, value, safety, and clinical effectiveness. There are countless groups in every good healthcare institution that “do ethics” — and members of ethics committees must reach out to join forces with them.

In conclusion, ethics committees continue to have a pivotal role in the provision of good healthcare. Perhaps their greatest role is to ask the right questions throughout every tier of the institution, and the question that grounds all the others is this: “For whom shall we care? On the answer to that question hangs an elegant and fitting response.

©Copyright 2006, by the Center for Practical Bioethics.
All Rights Reserved. To order additional copies, contact

Center for Practical Bioethics
Harzfeld Building
1111 Main Street, Suite 500
Kansas City, Missouri 64105-1329

816 221-1100, ext. 213
816 221-2002, fax
www.practicalbioethics.org
bioethic@practicalbioethics.org