



**Ethics Committee Handbook —
For New Members Orientation**
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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 Child Has a High Fever

In 1930, if your baby had a high fever, you would have given her half an aspirin and bathed her forehead with a towel. If the fever continued to rage, you might have called the family doctor. Night or day, he (almost all physicians were male) would have come to the house and prescribed care right then and there. If the child needed to be hospitalized, the doctor might himself have taken her there.

In the 21st century, in places and for families well served by a modern healthcare system, the scenario looks quite different. Nowadays, concerned parents wrap up their sick child and put her in the car. They drive to the nearest Emergency Room or Urgent Care, or they place a call to 911 and the ambulance arrives at the door in minutes. Parents may ride along, but they might well be asked to wait while strangers care for their sick child in a sterile environment called Hospital.

Grandma Is Dying

In 1930, Grandma would probably be living with one of her children as an important part of the household. When her health worsened such that Grandma was apparently dying, the doctor might have come to the home, more as a social visit than a professional one. He might have comforted the family and held Grandma's hand for a while. When she died, Grandma would do so in her own bed, surrounded by family. Grandma's physician and a clergyman might have joined the family in the kitchen afterwards to drink coffee and tell stories about her past or simply to help everyone grieve.

Today it is different for many or most elderly persons in their waning years. Grandma may be residing in a skilled nursing facility instead of with family, and she may have been there for several months or years. One of the aides will notice her decline and report it to the nurse on duty. The nurse 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. If she stops breathing or her heart stops beating, resuscitation may be attempted. If CPR is "successful," Grandma may survive long enough to die slowly in the isolation of an intensive care unit for a period of weeks or months-- until death finally, inevitably 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 will whisk her off to the hospital which, in turn, rushes Grandma into the ER and then intensive care. There she will die, little by little, with clinical interventions mostly prolonging her dying process.

What Do Those Scenarios Tell Us?

In less than a century, 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 severely limited in what it could do, has subsequently become linked to technology, which has revolutionized its practice.

- A century ago, nature often “took its course,” but now its course is radically altered with multiple options from which to choose.
- Most often, 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.
- Palliative care services now exist in most hospitals.
- Hospice has become a mainstay in healthcare delivery, but lengths of stay are still relatively short. Many hospice patients die within a few days of admission, having accessed optimal end of life care late in the dying process.

Ethics committees have been established to help patients and their families evaluate all available options and to ensure that the patient’s goals and values are known and respected. No less importantly, ethics committees are empowered to help healthcare providers fulfill their special roles and responsibilities in a technological and complicated age.

This orientation manual will introduce you to healthcare ethics. It will provide examples of thinking through clinical 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. Examples of each one will be provided. So 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), use of principles (duty-based), and 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 palliative care and the relationship of ethics committees to palliative care consultation;
- understand the organization of ethics committees and differentiate between various models of case consultation;
- use your new knowledge to help your institution’s ethics committee help patients, their families, and healthcare providers establish meaningful communication and solve ethical problems.

Having learned these skills, you likely will also be more confident about your contribution to the ethics committee.

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 action, their tools of choice will include ethical analysis and argument. This chapter will help you develop those skills.

Before we consider the work of an ethics committee, we must distinguish morality from ethics.ⁱ 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 whomever 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 are 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 morals 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, hairstyle 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 morality, similar to “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 rule denoting character—morality—but merely 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; and whether or not you did, it had no consequences for your character, though it might have affected your personality in some way. When you went home for an overnight visit, you likely made your bed in the morning, per usual in that home. You did so, not because neatness is part of a common morality, but because respect for your mother is.

It is necessary to think about the development 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.ⁱⁱ 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, since the early 1990s, our nation has been engaged in ethical argumentation regarding “physician assisted suicide” or “aid in dying.” The terminology used reflects the divergent perspectives that are taken. Participants in these arguments understand that what is concluded affects the meaning of medicine and its grounding in dictates of the Hippocratic Oath. Affected also is our understanding of the physician-patient relationship and the nature of the control we have over our own lives and deaths.

As we have spoken our convictions, listened to one another, or read arguments from across the nation, some communities perceived a growing consensus, which eventually led many states to prohibit physician-assisted suicide. Some others, starting with Oregon, have legally supported physician-assisted suicide, which is referred to in Oregon as “Death with Dignity.” The arguments continue, and not all of us are in agreement. This is ethics.

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 values or rules against one another and we must choose one while in violation of the other. Dilemma. Perhaps it is a situation in which there is an anticipated good outcome that can only be reached by inflicting the pain of surgery or the discomfort of chemotherapy. Doing harms to a patient requires caution and careful justification, using ethics. Another situation of moral dilemma might entail considering a 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.ⁱⁱⁱ When you use one of these ethical structures to help frame your argument, you force yourself to think critically and speak more exactly; thus you become more effective in convincing others of your position. Or you might learn from the compelling argument of another person that you were in fact morally mistaken.

Some examples of ethical argument:

1. Stealing is wrong because it usually makes the situation worse.
2. My granddad, whom I greatly admire, never stole, and taught me not to do so.
3. I have a duty to respect the property rights of others by not stealing what is theirs.

Each of the three reasons why stealing is wrong differs from the others because the basis for each is different. Recognizing that stealing usually makes things worse is a motivation not to steal because I want to avoid bad outcomes. Notice how different that reason is from the one in which I use my granddad as a model of virtue, as the example that keeps me honest. Fear of bad consequences is not a motivator here; rather, I am motivated by a moral exemplar. And when I tell you that it's my duty not to steal out of respect for property rights, that is yet another way to ground a moral against stealing.

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

"Stealing is wrong because it usually makes the situation worse" 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, the outcome for an owner of the stolen goods is bad – they lose access to their resources. Furthermore, the outcome for the person stealing may also be bad because they risk punishment if they are caught. For some utilitarians, there may be circumstances where the outcome of stealing will be good. Think of the mother who steals food or diapers for her children. Under those circumstances, stealing may be the "right" thing to do.

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 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 rightly suspect 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, because "it is the way a reasonable person would act,

“or because “I have a duty to . . . ,” it is likely a form of principlism. I am setting forth the principles 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 health she once enjoyed. She is dying, but it is not anything like a “good death.” Her discomfort and pain have not been addressed due to lack of resources for the sort of comfort care available to many of us now. The minister has just left her bedside and says to Cassie, a certified nurse assistant, “She’s ready to die anytime now. May God release this poor woman from her suffering!”

Cassie thinks, “Why should she have to wait? If she’s suffering, then I’ll help her. I will be the instrument of God’s mercy.” Cassie goes to the bed, places a pillow over her face and presses down. After a few minutes, she removes the pillow, makes sure the woman is dead, and calls the director of nursing to report that a patient has died in her sleep.

Consider:

1. Cassie’s action was legally wrong. Was it morally/ethically wrong?
2. If so, what wrong(s) were committed?
3. Explain your response(s).

Some possible Responses

Cassie’s action was morally wrong because:

- 1) life is a precious value, and one ought not deprive another of life except under extraordinary conditions
- 2) the elderly patient has a right to life and it is unjust to deny that right
- 3) one can go to jail for killing a person, no matter how ready one may be to die
- 4) killing generally leads to bad outcomes; e.g., the person killed loses all future good experiences, that person’s loved ones suffer due to their death, the person who kills risks punishment, etc.
- 5) my parents who were loving people taught me to show respect for others and to care for them
- 6) 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 arguments from a theory of consequences, 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 arguments 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.

Now look again at Cassie's actions. Cassie lied to her supervisor when she said the patient had just died in her sleep. Was Cassie wrong to lie? Why is lying wrong? We might say that lying, in this situation, was wrong because:

- 1) 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
- 2) the consequences of Cassie's lie are worse than the consequences of her telling the truth; for example, it would be better for Cassie to tell the truth and begin a discussion about end-of-life care in this situation; or, alternatively, it would be better for Cassie to tell the truth because she should not be allowed to continue working as a nurse's assistant
- 3) I do not want to be seen by my friends as a liar, but as someone whose word can be relied on; and Cassie should be motivated in this way, also.

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 while on nursing duty.
2. Your supervisor asks you to team up with a coworker who is always late for work. You don't want to do so.
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 an attractive patient.
5. A patient admits to you that she is not taking her medication but urges you not to tell the physician.

Sometimes our reasons for preferring one action over 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."

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.

Hospital Ethics Committees were 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). They were "institutionalized" by The Joint Commission on Accreditation of Hospital Operations (1992), now known as The Joint Commission (TJC).

TJC's Patient's Rights Mandate required that every accredited institution provide a mechanism for dealing with ethical conflict. Although TJC 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 often 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 they 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 transplantation and moving into multi-organ transplants. In the 1970s, attention focused on bionics, especially the artificial heart. In the 1980s, our concern was genetics. In the '90s, artificial intelligence took to the fore. Today, genetic interventions and individualized/personalized medicine is becoming common.

Consumerism

During recent decades, the human and civil rights movements forced medicine away from its paternalistic stance and increased emphasis on patient's rights and patient autonomy. Most 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 on the long-term effects of syphilis, uneducated and vulnerable African Americans were not told about the benefit of penicillin or offered antibiotic treatment, even though its therapeutic effects were well known at the time. As a result of "Tuskegee" and some other major research violations, public confidence in government-sponsored healthcare research was shaken. The Tuskegee atrocities were widely reported and are often cited as the beginning of skepticism about medicine and biomedical research.

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. It ultimately ruled that adults have a right to choose or refuse any medical or surgical treatment. And the next year, 1991, the Patient Self Determination Act (PSDA) was passed by Congress. The PSDA 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.

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?

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.

It became acceptable to initiate discussions about rationing healthcare. In 1987, Daniel 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.

In 2010, the Patient Protection and Affordable Care Act became federal law. The ACA, or "Obamacare" as it often was called, led to major healthcare reform, including shifting reimbursement from a volume basis to being driven by outcomes and patient values.

Technology, consumerism, and cost containment have become dominant factors in changing the face of medicine. The new medical model that emerged is directly related to the organization of ethics committees. Shared decision making characterizes the new model. That physicians are no longer the single decision makers has also required a new vision of physician/patient relationships, and together these changes have 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 increasingly characterized as technicians or engineers (emphasizing the importance technology has come to play in the practice of medicine) or as gatekeepers (stressing the place third party payers 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 recipients of healthcare. Today the terms “patient-centered care” and “evidence-based medicine” are common and vie for prominence in decision making.

No discussion of the history of the changing face of medicine is complete without reference to the growing role of third party payers. Patients fortunate enough to have insurance are controlled by government and corporate decisions regarding their healthcare benefits. Corporate purchasers may move large blocks of patients from one provider network to another. Long term relationships between provider and consumer sometimes have been severed; financial disincentives have forced change. The result is that many patients have no relationship with a primary care physician. For those covered by public insurance, Medicare and Medicaid may determine treatments and medications that patients do or do not have access to.

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 deductibles and 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.

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.

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 persistent 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 multi-disciplinary committees (which the author called “ethics committees”) could be of assistance in making decisions about withholding or withdrawing

life support. In the text of the Quinlan case, the judge said that if the 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.”

The Joint Commission (TJC). In 1988, TJC issued a DNR (Do Not Resuscitate) mandate that included an “ethics component.” In 1992, TJC’s Patient’s 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 surrogate support. Ethics committees do provide a forum for discussion with interested parties. Indeed, their members, who hopefully 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 trustworthy and trusting so as to establish a culture in which members will be comfortable asking for clarification and revealing their own ignorance. An effective ethics committee is one also in which members can challenge one another to provide an ethics 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 recruited and/or approved to serve on the committee?
3. What concerns do you have about serving on an ethics committee?
4. What might be your greatest contribution to the committee?
5. What is something you will need to work on to become a better ethics committee 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 continuously 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:

1. Update oneself, or keep up with, the fundamental theories and axioms of medical ethics, a study that also includes reviewing the history of medical ethics.
2. Develop clinical ethics skills.
3. Conduct ethics consults.
4. Develop practice guidelines from these consults that can be adopted as hospital policy by other committees and boards of the institution.
5. Contribute to the institutional conscience by helping 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 ongoing 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, though other readings may be of use. Ethics, like any discipline, has its fundamental theories (e.g., utilitarianism, virtue, and principle ethics) and basic starting points for discussion.

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 to discuss the ideas and concepts that are being studied. 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: MM is 89 years old, her blood pressure is 86/46, 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, and 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:

1. Gather facts.
2. Clarify ethical issues (e.g., what values are in conflict? are there differences of opinions about the consequences of different actions?).
3. Discuss stakeholders’ interests (e.g., who has interests and what are those interests?).
4. Decide on one or more alternatives with justification for each alternative. This explanation will be presented to the one requesting the consult.
5. 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 the hospital for four months, the majority of time in the ICU. RT 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 on a ventilator. She has a permanent pacemaker and weighs only 75 pounds (down from 110 pounds at her admission).

Throughout her hospitalization, her children 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 carrying out a code on 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 the 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 impediment 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 (nonmaleficence) and their attempt to provide proper palliative care to the patient (beneficence). (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. What other stakeholders share in this dilemma?

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 and symptom management (often patients and their families feel that they will be abandoned if aggressive care ceases).

Offer the translator, clergy person, and family friend 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 initiated.

Evaluating the outcome. Had this 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, amending it as desirable. Likewise, if case consults appear to center on a limited range of issues (e.g., end-of-life care, treatment redirection [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 healthcare 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 of 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 committees 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.

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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 Regional Hospital Ethics Committee Consortium, email bioethic@practicalbioethics.com. We welcome your visits and your suggestions.

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 2,000 individuals, organizations, and institutions. This website 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.”

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

The Georgetown Kennedy Center lists additional online resources:
<https://bioethics.georgetown.edu/explore-bioethics/online-bioethics-resources/>.

National Institutes of Health at www.nih.gov/sigs/ 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, try 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 at <http://bioethics.pitt.edu/>. If you forget this address, go to www.pitt.edu, click on “search” and click on “bioethics.” This site is very useful.

European Group on Ethics at <https://ec.europa.eu/research/ege/index.cfm>. 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 at <http://www.bioethics.umn.edu> 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.
- 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 turn 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 she agrees with Mary because she lacks clarity on her own about Jennie’s wishes, or she may agree with Mary because she feels Mary 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 hers 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 Chapter 1 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 conscience 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. 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 those found on the Center for Practical Bioethics website, www.practicalbioethics.org. 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.

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.

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 policies of patient's rights 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 hospital-wide 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:

1. Statement of the policy
2. A statement of the ethical principles underlying the policy
3. Definitions
4. Procedures
5. 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
- non-beneficial 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 experts 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 mandatory practice at XY Hospital for patients with a Do Not Attempt Resuscitation (DNAR) order involves placing a purple bracelet.

A purple bracelet must be placed on the wrist of any patient who is DNAR.

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 ongoing 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. Is it consistent with other related institutional policies and procedures?
3. Are the ethical principles expressed clearly? If not, how can they best be articulated?
4. Are the requisite definitions attached to the document?
5. Have you determined that proper procedures are in place to effect the policy?
6. Were your implementation plan and evaluation measures clearly stated and properly carried out?
7. Have others in your institution been consulted and/or educated about the policy?

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 Hospital 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 TJC 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 Life-sustaining Consortium of the Center for Practical Bioethics

Executive Summary

Considerations Regarding Withholding/ Withdrawing Life-Sustaining Treatment was published in 1992, and revised in 1995, 1997, 2004 and 2015. The basic principles established in the original document endure; however, decisions to withhold or withdraw life-sustaining treatment involve serious ethical issues in the context of the current healthcare delivery environment. Periodic review of the guidelines ensures that ethics committees and their organizations will have fresh and relevant guidance as they review cases, develop educational programs, and help formulate policies within their organizations.

The following issues received additional emphases in the revised document:

- decision making for people who are unbefriended and incapacitated;
- how physicians may respond to requests for treatments they consider ethically inappropriate;
- the increasing acceptance of, and capacity to provide, palliative care; and
- shifting from “futile” care to “non-beneficial” care.

Decisions to forgo life-sustaining treatment pose significant difficulties for providers, patients, and families. Medical boards, legal associations, and many other thought leaders support patient choice, but providers and families are often reluctant to act on decisions that reflect these choices because of personal values, professional standards, and/or perceived legal risks.

There is increasing data that providing palliative care to those who are seriously ill and dying improves quality and outcomes and actually prolongs life.

The revised guidelines provide support and resources to healthcare providers, patients, and families to help them determine whether withholding/withdrawing life-sustaining treatment is the most appropriate treatment they can offer to their patients and loved ones.

After careful deliberation, the Consortium was unable to achieve consensus on the issue of futile treatment beyond the language included in the document. The Consortium will consider this important issue in separate deliberations beginning in 2005.

August 2004

The Kansas City Area Ethics Committee Consortium is among the oldest ongoing groups of its kind in the United States. The Consortium is composed of representatives from more than three dozen hospital ethics committees, meeting every other month to discuss complex cases, share educational opportunities, and develop policy guidelines. More than a dozen guidelines documents have been created and widely disseminated on issues ranging from withholding and withdrawing life support to ethical issues in managed care, to difficult patient-provider relationships.

Copies of Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment can be obtained by calling the Center for Practical Bioethics at 816 221-1100 or email the Center at bioethic@practicalbioethics.org.

Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment

Kansas City Area Ethics Life-sustaining Consortium of the Center for Practical Bioethics

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 guideline is all-inclusive. 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, ethics committees, palliative care consultation services, risk managers, and others about ethical issues related to withholding/withdrawing life-sustaining treatment.
- B. Protect patients from unwanted treatment and treatments that are potentially harmful.
- C. Provide support to healthcare providers who believe withholding/withdrawing life-sustaining treatment is the most appropriate treatment option.
- D. Establish a coherent philosophical/ethical foundation to help ethics life-sustaining become more effective when providing case consultation involving withholding/withdrawing life-sustaining treatment.
- E. Empower institutions to facilitate appropriate discussion of withholding/withdrawing life-sustaining treatment.
- F. Promote the integration of palliative care.
- G. 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.
- K. Palliative care is not yet universally available to all patients.

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. Non-beneficial care — 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. It has been proven that those who receive palliative care live longer.

- 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, assisted suicide 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 the 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. Treatment that is unwanted and/or deemed "non-beneficial" may cause additional harm and suffering to patients.
- H. 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.
- I. 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.
- J. 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 healthcare 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. (Affirmed by the US Supreme Court in 1990 – Cruzan case)
- (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 care team and/or 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. In such cases, the decision-making process and justification for the

decision should be well documented. Consultation with the ethics committee may be helpful.

C. Role of the Healthcare Provider

Providers have a responsibility to advocate for the well-being 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 consistent with standards of practice 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. Non-beneficial Treatment

Non-beneficial 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. Providing non-beneficial treatment may increase the patient's pain and suffering and shorten life.

- (1) If the care providers directly involved in the care of the patient agree that a treatment is non-beneficial, 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 non-beneficial.
- (3) If a patient, the patient's surrogate, or physician requests a non-beneficial 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 non-beneficial treatment, he or she is morally obligated not to abandon the patient.
- (4) Involving the court in conflicts related to medical decision-making 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. Ethics Committee consultation may be helpful and/or required in such cases.

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 institution can fulfill its responsibilities to these persons through a wide range of mechanisms, including 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 life-sustaining are advocacy, case consultation, and policy review and development.
 - (a) The primary role of the ethics life-sustaining is to assure that the patient's goals and values are heard and respected.

- (b) The ethics committee provides 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) Ethics committee 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.
- (e) 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.

This document was completed in 1992 with revisions in 1995, 1997, 2004 and 2015.
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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.

History also was working directly against us: the chaos of healthcare delivery nationwide has resulted in many millions of Americans uninsured or underinsured, at sometimes up to 27 percent of the population. We deemed ourselves helpless in this rampant tide. Likewise, 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 earlier, 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 boards of directors 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.

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Chapter 1 Notes:

ⁱTom 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.”

ⁱⁱ “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).

ⁱⁱⁱ 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*.