Section 1 The Context of Healthcare Ethics Committee Work

Chapter 1

Introduction to healthcare ethics committees

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Objectives

1. Explain how the understanding and function of ethics committees have developed in the concept of modern healthcare.
2. Define the relationship between clinical ethics consultation and the ethics committee.
3. Describe the roles, constitution, and authority of ethics committees in institutions.

Case

Isaiah is a 56-year-old construction foreman who arrived by ambulance at University Hospital after falling from a sixth-story scaffolding that had been improperly installed. Emergency surgery stabilized his condition, and he remains in the Surgical Intensive Care Unit (SICU). Three weeks post-surgery he is breathing on his own, but has made little additional neurological progress. The neurosurgery team has given Isaiah a poor prognosis for recovery, and considers further aggressive medical treatment to constitute "futile care."

Isaiah and his second wife, Shirley, have been married for 2 years. When the treatment team discusses the possibility of transitioning Isaiah to comfort care, Shirley defers decision-making authority to Isaiah's three adult children: Evan (28), Tamara (23), and Jack (19). Evan and Tamara, while both close to their father, disagree on what they think he would want in this situation: Evan assures the team his dad would not want to live "like a vegetable," but Tamara insists that her dad views all life as sacred and therefore she wants "everything done." They both agree that Jack, who lived with their dad most recently before his deployment to Afghanistan with the US Army, would have the best sense of Isaiah's wishes, and both of them insist that Jack would agree with each of them.

Introduction–Ethics in the hospitals: a brief history

Isaiah's case is unaccountably tragic: a previously healthy man suffers a misfortune and is unlikely to have a good outcome. The unexpected nature of this tragedy is part of what makes it so heartbreaking and may, in fact, contribute significantly to the inability of the family members to come to an agreement about the appropriate course of action for their loved one. But in addition, there may be some important value conflicts that are reflected in the

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family's approaches to decision-making: quality vs. quantity of life, authority and resources for decision-making, and fundamental existential values are all under debate in Isaiah's case. The atmosphere surrounding this case is charged with emotion and frustration, both for the family and the healthcare providers, all of whom share the goal of acting in Isaiah's best interests. These feelings are intensified by logistical challenges, conflicting visions of the good, and complicated family dynamics.

Cases like Isaiah's often benefit from a dispassionate review by a group that is not directly involved in his care but is familiar with cases like this one. Such a group might diffuse tensions, clarify the meaning of terms like "medical futility" and "comfort care," and suggest a way to reconcile conflicting obligations. They might then create educational programs to prepare the staff for similar situations in the future. They might even develop policies that would help resolve future conflicts that appear intractable. These three activities in fact constitute the typical charge of a Healthcare Ethics Committee (HEC).

The idea of an institutional *committee* to address ethical problems is a relatively recent one. The most influential stimulus for the creation and proliferation of ethics committees has been the Joint Commission on the Accreditation of Healthcare Organizations (The Joint Commission), which began in 1992 to require some kind of formal "mechanism" to assure that ethical issues in patient care were addressed effectively. However, the origins of HECs can be traced to the dialysis allocation decisions of Catholic Medical-Moral committees (sometimes known as "God Squads"), of the 1960s, the end-of-life committees recommended by the Quinlan ruling (1976) and the President's Commission (1983), and the neonatal review requirements of the Baby Doe Regulations (1984).

A number of influential organizations have subsequently endorsed the concept of HECs, including the American Hospital Association (1986) and the American Medical Association (1985). Exact numbers are not available, but a conservative estimate would be that 30,000 people (and probably double that) in the United States currently serve in some manner on an HEC (Fox *et al.*, 2007). Since there are only around 1700 members of the American Society for Bioethics and Humanities (ASBH), the dominant professional organization in bioethics, it is apparent that the great majority of HEC members would not identify themselves as professionals in the field of healthcare ethics and thus may find themselves uncomfortable in their role as a "go-to" person for ethical concerns in the hospital. The present volume hopes to reduce that discomfort by preparing HEC members for the challenges they are likely to face in this role.

Three functions of HECs

The traditional threefold mission of an HEC has not changed substantially since the President's Commission formulated it in 1983. The most visible and controversial role is to consult on difficult clinical decisions. Equally important, though sometimes forgotten, are the other two functions: formulating institutional policies (consistent with the organization's function and mission) to guide the professional staff in making ethical decisions, and educating hospital personnel about these policies and about healthcare ethics in general. The case at the beginning of this chapter alluded to all three functions: the HEC might be called in to consult with the staff and family, it might be asked to develop a policy for conflict resolution, and it might be asked to provide staff with further education about the ethical and legal considerations. We have devoted a section of this book to each of these topics, and only briefly discuss them here.

Function 1: Case consultation

When an acute ethical problem arises in clinical care, we need individuals with special education and/or experience to address it; this describes the need for the ethical case consultation. The consultative role of the HEC may vary both in terms of the goal of the process and the model of consultation. Goals for the process may include clarifying the situation and/or providing recommendations, ensuring effective communication among diverse groups, empowering clinical staff to assess and address ethical issues themselves, and recognizing patterns of consultation that may result in broader educational or policy implications (see Chapter 5 for more on this). Regardless, several different models are effective ways of achieving these ends; brief descriptions of the three most common models follow below.

1. **Full-committee (multidisciplinary) consultation**: When HECs first appeared in hospitals, the full membership of the committee handled case consultations. Implied by court decisions like Quinlan and regulations like those following Baby Doe, consultation by full committee is intended to bring a wide variety of perspectives to bear on complex ethical issues in clinical care. However, because of the size of most committees, it is difficult to call the committee expediently, to get the committee into the clinical environment where cases occur, and to avoid overwhelming invited participants like staff, family, and patients. While still prevalent and possibly quite successful for long-term care facilities where the need to react to ethical issues is less acute, because of the problems raised by the use of a full-committee model, this approach is not recommended for most institutions.

2. **Individual consultant**: At the other personnel-usage extreme is the use of an individual ethics consultant. Most common in large institutions with deep resources, individuals specially trained in bioethics can serve as primary ethics consultants. S/he typically has studied healthcare ethics (formally or informally), has demonstrated competence in an academic discipline that informs the field (such as philosophy or religion), and is familiar with the clinical setting. This person can respond quickly to a request for help and can meet with key individuals in an efficient manner. Given the need for a targeted education and the cost of paying for such expertise, this model is not available to many, maybe most, hospitals.

3. **Consultation subcommittee**: The third approach involves the appointment of select members of an HEC onto a consultation subcommittee. With education and experience, members of an existing HEC can become proficient in collaborative consultation. Over time, members of the group are chosen for their special abilities and ready availability to provide help. This "team model" attempts to incorporate some of the best features of both the individual consultant and the whole committee models. Like the individual consultant, a small group that is "on call" is able to respond quickly to an urgent need, can be flexible in meeting with involved parties in various locations in the hospital, and is less intimidating to patients and families. Additionally, as an interdisciplinary group, it would be expected to contain different ethical perspectives as well as differing sets of skills and experience.

Choosing from among these models involves matching the needs, resources, and scope of the HEC to the institution or organization more broadly.

In addition, as a professional organization, ASBH has a subcommittee working diligently on the creation and implementation of a certification/credentialing process for

ethics consultants. The idea is to standardize the skills, knowledge, and attitudes of ethics consultants, in order to ensure that those practicing in the field share a certain competency level. While it is a bit early to project exactly what form this credentialing will take, it is likely that members of HECs who perform consultations will be encouraged to become credentialed.

Function 2: Policy development, review, and implementation

Every hospital has policies that deal with ethical concerns. Some are obviously ethical in nature, such as policies that govern advance directives. Others that are not overtly ethical in content may still have ethical dimensions – for example, policies concerning admission, discharge, and transfer of patients. When done well, writing or revising policies provides HEC members with an opportunity to engage in meaningful interdisciplinary work with the clinical departments likely affected by the (proposed) policy. Policy work is some of the most important work undertaken by HECs: the ethical climate of any institution is determined in large part by the policies it adopts. This is particularly true when considering policies that govern the organization. While HECs may not take full responsibility for what the Joint Commission calls "organizational ethics," ethics committees may indeed have a role in addressing the organization's mission by shaping the institution's policies on workplace conduct, hiring practices, and the allocation of resources broadly construed. Moreover, by offering reasonably clear guidelines for difficult situations, good policies help individuals make good decisions and thus prevent some ethical problems from arising.

Function 3: Education

The educational role of an HEC is twofold: internal and external. As we have noted, the great majority of HEC members probably have little academic training or other formal background in the area of ethics, generally, or in the field of healthcare ethics, more specifically; some training, then, is necessary for this new role. But in addition to this, an HEC should also provide education to the entire hospital community. This becomes particularly important when policy is adopted or revised that has ethical dimensions, when a specific ethical concern comes to the committee repeatedly or for some other reason seems to gain traction in the institution, or simply to address perennial issues in healthcare ethics like surrogate decision-making or the allocation of scarce resources. Such initiatives can forestall problems that arise from lack of awareness and can enhance the visibility and credibility of the committee.

HEC constitution and authority

As noted previously, the Joint Commission makes no pronouncements about how to constitute a "mechanism" to address ethical concerns. Thus there are no authoritative guidelines about how the committee should be developed – its administrative location, its charge, and its membership. In looking at what benefits a committee might bring to its institution, however, the design of the committee begins to come clear.

Location and accountability

All institutional committees are established by a particular administrative unit. They are given a purpose or charge and are responsible for reporting on their activities to the parent unit. Most HECs have been created by the medical staff or the hospital administration,

though some have been established by the hospital's board of directors. Although it may not be a crucial decision, the location of the HEC in the institution's administrative structure can have some practical consequences, since guidelines for constituting and operating the committee may vary according to the group to which it reports. In some hospitals, for example, medical staff committees must be chaired by physicians, thus restricting the options for filling this important position. On the other hand, as a medical staff committee intent on quality improvement, it may be easier to shield proceedings of the HEC from any potential legal scrutiny.

In some institutions the organized medical staff is skeptical or even mistrustful of the concept of an ethics committee. In such cases it might be advisable to establish the HEC as a unit of the hospital administration. If it is an administrative committee, however, its purpose must not be perceived as making the hospital run smoothly. The third possibility, board committee status, can carry both positive and negative messages. On the one hand, the HEC is answerable only to the highest authority, which gives it significant status. On the other, this may carry the implication that its purpose is to oversee and perhaps report on medical and administrative decisions, creating distance from the very people it is intended to help. Given all these potential benefits and detriments, the best place for an HEC to be located organizationally may involve many subtle factors that vary from place to place and may change over time in any given institution.

Leadership

Committees are rarely effective if they do not have good leadership. Thus the chair of an HEC is always a critical position to fill. The chair(s) will become the de facto face of the committee and should be someone who enjoys respect and credibility among all professions in the institution. The most important quality, however, is commitment to the idea of an HEC. The chair must believe in the mission of the committee and consider the position an important part of his or her job. Meetings will be perfunctory and unproductive unless the chair takes care to construct a meaningful agenda.

Where should one look for a suitable chair? There are good reasons to support a physician as chair of an HEC. A physician chair tends to have more immediate credibility with physician colleagues, perhaps making it easier for them to call on the committee for help. As we have noted, in some institutions, the committee is under the auspices of the medical staff, and only a physician is allowed to function as chair. However, in other hospitals, no such rules exist, so there may be a diversity of leaders. A professional ethicist may chair the committee in these instances, which lends credibility to the work of the group, given the professional training and general expertise of the leader. This will work only in cases where the committee and the chair are well-respected members of the organizational community, and where the chair has clear partners with other key stakeholders. Nurses, social workers, and other healthcare professionals may serve well as chairs, too. Regardless, there are no hard-and-fast rules; committee founders need to assess the available resources and the pragmatics of the institution to determine who should chair the HEC.

Membership and structure

An ethics committee allows for an array of knowledge and perspectives to be brought to bear on consultation, education, and policy issues; otherwise, the ethics "mechanism" of the hospital might as well be served by one or two individuals. Thus the committee should be

multidisciplinary, composed of members with a variety of professional perspectives and disciplines on clinical care (physicians, nurses, allied health professionals) and on broader social issues (for example, social workers and ethicists). Second, a committee allows for a variety of expertise. Since general familiarity with ethical issues in healthcare is clearly desirable, particular physicians and nurses with training or deep interest in ethical issues are obvious targets for membership. At the same time, policies or cases tend to cluster in, or overly affect, certain units. Thus, it might be important to have, say, a critical care specialist on the committee, as cases from acute care units are often fraught with ethical concern.

While special knowledge is desirable on the committee, some areas of expertise deserve special note. For example, some committees include a member of the hospital's risk management or legal team, and some include members of hospital administration. In these particular cases, conflicts of interest are the primary concern. While ethics committees are *institutional* committees, they are charged to be "objective" in their deliberations, looking out for what is the best solution to a difficult case or complicated policy from a dispassionate perspective. As a result, the outcome of deliberation may not be an action that is in the best interests of the institution more generally. Thus, to the extent that the risk manager or hospital administrator also has a responsibility to protect the institution, this conflict of interest may raise tensions given their roles. On the other hand, having a representative from hospital administration or risk management could prove quite beneficial to the committee; this is particularly true when the committee considers organization-level decisions (like policies on resource allocation) or when there are real questions about how a state statute may apply in a particular case. In addition, having a member of hospital administration on the committee may lend legitimacy, and may enable resources to be allocated to the committee for education or other purposes that might otherwise be devoted elsewhere. Regardless, these are issues about which an HEC should be thoughtful when deciding on its composition.

Another unique category of membership is that of the "community" member. While not a requirement, many HECs, perhaps structuring themselves after the IRB model, employ community members – that is, persons not directly associated with the institution. The purpose of the role is to provide a kind of corrective should the institutional members of the committee become insulated from public perceptions or too interested in institutional protection. This is a daunting role to perform. It may be difficult to identify persons to fill the role. In fact, the person filling the role often has some relationship with the institution (e.g., ex-patient, former employee, spouse of an employee, etc.), raising questions whether that individual can adequately fulfill the intended role of the community member. Nevertheless, some committees may find it useful to have a community member on the committee, especially if the committee is particularly involved with issues that impact the community directly.

In addition to their knowledge and positions in the institution, a number of personal qualities of its members are critical to the success of an HEC. Members must believe in the importance of the committee's work and be willing to devote significant time and energy to it. They should also try to take advantage of opportunities for self-education. Moreover, for an HEC to function smoothly and effectively, members must respect one another and the various perspectives they represent; egalitarianism should pervade the committee's work. Differences of status within the organization should be left at the committee room door: it is cogency of reasoning that should matter, not position in the institution. Members should be respectful but not deferential to one another, and anyone who expects deference should be dropped from the committee.

Bylaws

Like any other working committee, an HEC needs a set of bylaws or a detailed committee charge to give it structure and allow for necessary changes in an orderly manner. In addition to leadership and categories of membership, the bylaws should address terms of membership, frequency of meetings, and the scope of the three roles of consultation, policy review, and education.

Length of service on the committee can be an important matter. Short terms and a rapidly rotating membership will result in instability and inexperience, whereas indefinite or permanent membership may burden a committee with uninterested and unproductive members. The best solution is probably a compromise, such as fixed terms of 2 or 3 years with the possibility of reappointment. Uninvolved members can easily be dropped and committed ones retained as long as they contribute to the group.

Frequency of meetings is another item the bylaws should address. Regular meetings should be mandated. It is easy for overburdened professionals to slip into the "only when necessary" mode, which in effect means only when there is a consult to conduct. Without regular meetings, however, the "preventive" work of the committee – education and policy review – will suffer. Self-education and self-assessment will also falter, affecting the quality of the consults, and the committee will lose a sense of its continuing importance to the life of the hospital. Quarterly meetings are the minimum to retain a sense of continuity, with more frequent meetings highly desirable.

The bylaws should define as clearly as possible the role that the HEC is to play in all three of its primary activities. The educational function will probably be left entirely to the committee to design and implement programs that it can offer on its own or through departmental meetings (again, having a budget for this purpose is highly desirable). The bylaws might, however, specify a base level of ethics education that committee members themselves should have.

With respect to policy review, the HEC may be charged to recommend changes to the administration or to the medical board. In this it is similar to every other committee in the institution, as committees are generally created to make recommendations rather than final decisions about policy matters. If there are particular policies the committee is to "own" or review regularly, they should be specified in the bylaws. And, in other situations, the HEC may initiate the creation of a policy based on a series of clinical consultations; members should consult institutional procedures for performing such an action.

The most important function to clarify in the committee's bylaws is case consultation, since there may be uncertainty what kind of outcome to expect. Although, in general, committees are charged to make recommendations to others, some are in fact constituted to make binding decisions about particular cases. Nevertheless, there is sometimes considerable apprehension about the ethics committee "taking control" of a case when called to consult. Committee bylaws should specify that the committee is advisory only and does not make decisions about patient care. Some committees build this into their name (e.g. "Medical Ethics Advisory Committee") to make clear the limit to their authority. There may be a small subset of cases that the committee is given explicit authority to decide; if so, these should be spelled out carefully in the committee bylaws.

Conclusion

The Healthcare Ethics Committee is now a fixture in American hospitals, yet, like any complex institution, it is still defining itself. The concept has been scrutinized in the scholarly

and professional literature for some 20 years, including several books and countless articles focused on the consultative function of an HEC. There are ethics committee networks in several states and regions of the country. There is no lack of resources to aid an institution in organizing, educating, or revivifying a moribund committee. In the end, however, the general idea of an HEC must be adapted to the particular structure, mission, and size of the institution, and just as important, to its professional and community resources. This book can help, by presenting current thinking about major issues to be considered, indicating resources for further information, and suggesting ways to tailor an HEC to fit local conditions.

Discussion questions

1. *Conceptual:* What institutional barriers and attitudes do you anticipate posing challenges for how the HEC is viewed by staff, patients, and families?
2. *Pragmatic:* Which of the three functions of HECs presents the greatest challenge to your institution, and what can you do to overcome these challenges?
3. *Strategic:* How ought the bylaws and membership of your own HEC be constituted, given the needs of your organization and the expertise of your personnel?

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Section 1 The Context of Healthcare Ethics Committee Work

Chapter 2

Brief introduction to ethics and ethical theory

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Objectives

1. Explain how the terms ethics and morality refer to a family of related concepts.
2. Identify a variety of common sources of moral guidance and authority.
3. Describe several approaches to ethics and explain the value of ethical discourse (a systematic approach to ethics).
4. Use an ethical theory and its associated methods to help identify, clarify, and analyze clinical ethics issues.

Case

Janet S. is a 65-year-old stage 4 breast cancer patient whose third round of chemotherapy has failed. She knows her status well, as she suffers from significant pain from bone metastases. In thoughtful conversation with you, her oncologist, she asks for your help in hastening her death. She states clearly to you that she finds her life insufferable and that dying quickly while she still has some "dignity" is of utmost importance to her. She has made peace with her friends and family and states that she is ready to die.

Introduction: The meaning of "ethics"

"Ethics" is a term that lends itself to multiple meanings. Beginning with an understanding of both definitional *and* conceptual differences among these meanings provides a starting place to diffuse tensions caused by such differences and may help to clarify the purpose of HECs in an organization.

We begin with the colloquial use of the term "ethics." Simply put, ethics concerns how each individual deals with "right" and "wrong," "good" and "bad." We talk about our personal ethics, and frankly most, if not all, of us believe we are good people who have "ethics." This sense of ethics is tied closely to *values* and *character*.

In addition, though, we also recognize that when we are members of a profession we might be governed by "ethics." This governing is often manifest in Codes of Ethics or other lists of expected professional behavior, but it also resides in our sense of what being a professional is all about – the responsibilities and obligations that come along with the actions we

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perform in our roles as healthcare professionals. This sense of ethics is often associated with judgments of what actions or behaviors are *right* and *wrong*.

Finally, we carry with us our values and interests, and we begin to recognize that others, too, have their own interests as well. Further, the roles we play, not only as professionals but as family members, friends, citizens, and members of multiple communities each carry corresponding obligations. Often, between personal interests, cultural values, professional and relational obligations, it is not uncommon to find ourselves in conflict with others, with institutions, even with the many aspects of ourselves. Here conflicting concerns often lead to questions concerning ends we really should pursue and what means are appropriate in those pursuits. This sense of ethics can be characterized as weighing *good* and *bad*, *better* and *worse*.

No one of these three senses of "ethics" should be ignored, nor is any one of them always dominant. It is worth noting that each of us is a "values carrier," whether as a product of biology, nurturing, education, or some other means. Further, we do, in fact, find ourselves in relation to others – familial, professional, and so forth – and those relationships commit us to others and to expectations for which we are held accountable. At the same time, in a finite universe of limited abilities and resources, with a plurality of individual and communal interests, we are confronted often by concerns for what we should do, and why.

Ethics, then, concerns each of these aspects of moral living – values (character), duties (roles), and goods (ends). We might say, then, the "field" of ethics – i.e., the territory of values and interests covered by moral considerations – comprises those *evaluations* of human (and some other animal) conduct, both arising from and affecting character, which result in appraisals of "good" and "bad," "right" and "wrong."

Value conflicts in healthcare

Clearly, while ethics covers a lot of ground, it is part-and-parcel of human living, and yet a reasonable question still remains: Why *study* ethics? This question is brought into even greater focus if we limit ourselves specifically to healthcare as a profession. Each of us has a set of personal values that has helped shape us into the kinds of people who pursued the "healing professions." Also, professions have Codes of Ethics or other standardized lists of acceptable behaviors. This might seem to be enough. What role does a rigorous focus on ethics, medical ethics, or even just ethics committees play?

To answer this question, consider Janet's case from the beginning of this chapter. Simply relying on the fact that you are a "good" person and that you recognize professional obligations may not be enough to settle the moral issue for you. These features may help you begin to think about the issue, but they may in fact *produce* the value tension here: you may have personal or religious commitments that prevent you from hastening someone's death, but also have professional commitments to alleviate suffering to the best of your ability. How do you know which values should have priority in this situation?

The point is that no matter how "ethically equipped" we seem to be, value conflicts will arise in healthcare. Frankly, resolving ethical conflict is not always an easy task, and this makes ethical reflection all the more important. At the same time, ethical reflection is incapable of stopping at the "borders" of the particular conflict in front of us. Each consideration raises issues of "principle" rather than just expediency; thus, reconsideration of our professional obligations as well as our individual values is implicated in our ethical decision-making. Furthermore, it is also the case that our values and professional obligations are the products of past experiences, yet this still may not help. On the one hand, it is impossible