Section 1 The Context of Healthcare Ethics Committee Work

Chapter 1

Introduction

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Objectives

Upon reading and considering the content of this chapter, the reader should be able to:

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

Ethics in the Hospital: A Brief History

Case

Conrad is a 68-year-old former parole officer. He has been in the hospital for the past week on the oncology service. He has a sarcoma in his shoulder that the physicians are saying is inoperable, and that they believe he will ultimately die from complications of this cancer. When talking about this with Conrad and his family, however, the physicians become frustrated because Conrad, while aware of others in the room, does not seem to understand anything that is going on, and the family dynamics are challenging.

Conrad's family consists of three children and his girlfriend of 30 years with whom he lives. One of the children is from this relationship while the other two are from his former wife. The oldest, a son named Artemis, is constantly at the bedside, and he refuses to acknowledge the others in the family. The team, out of confusion and expediency, treats Artemis as the primary decision maker, and when he instructs the nursing staff to keep the other children and the girlfriend away, the staff feel obligated to do so. Meanwhile, the rest of the family are confused and frustrated by the lack of information since they cannot even call in because Artemis keeps changing the call-in password to give to the hospital.

Meanwhile, Conrad lies in the hospital getting intensive medical treatments, insisted upon by Artemis, that the team does not believe will make any long-term difference to Conrad's eventual demise. On the few opportunities that the other children have been able to talk with the team, they do not think their dad should continue on intensive treatments but should be transitioned to home hospice.

Conrad's case is sadly frustrating for most everyone involved, and all the while he lies in a kind of medical limbo that might stretch on for months. While everyone believes they are doing what is in Conrad's interests, the complex family dynamics, the tragic state of Conrad's disease, and the team's inability to navigate all this successfully make knowing whether or not Conrad is getting the care he wants and deserves hard to determine. In addition, there are some important value conflicts that are reflected in the family's

approaches to decision-making: quality versus quantity of life, authority and resources for decision-making, and fundamental existential values may all be under debate in Conrad's case. The atmosphere surrounding this case is charged with emotion and frustration, both for the family and the healthcare providers.

Cases like Conrad's often benefit from review by a group that is not directly involved in the care of the patient but is familiar with cases like this one. Such a group might be able to diffuse tensions, clarify the meaning of terms like "medical futility" and "comfort care," and suggest a way to reconcile conflicting obligations. Further, they could create educational programs to prepare the staff for similar situations in the future, and even develop policies that would help resolve future conflicts that appear intractable. Such a group is a healthcare ethics committee (HEC), whose purpose is to improve the quality and delivery of health care through the identification, analysis, and resolution of ethical questions or concerns.

While now ubiquitous in hospitals in the USA (though less so in other parts of the world) (McLean, 2007; Hajibabaee et al., 2016), the presence of an institutional *committee* to address ethical problems is a relatively recent one. The origins of HECs can be traced to the allocation decision committees of the 1960s (sometimes known as "God Squads"), 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). Particularly since the President's Commission's promotion of and outline for HECs, a number of influential organizations have subsequently endorsed the concept of HECs, including the American Hospital Association (1986) and the American Medical Association (1985; see Ethical and Judicial Council, 1985). However, in the USA, the most influential stimulus for the creation and proliferation of ethics committee is 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 (The Joint Commission, 1992). It is worth noting that The Joint Commission language has changed over the decades, moving away from "mechanism" to "framework" and "process," but still much of the responsibility for implementing that framework or process falls to an HEC.

As we come into the second decade of the 2000s, most US, Canadian, and European hospitals have an HEC, with the percentages lower but still existent in Asian Pacific and Middle Eastern countries (Hajibabaee et al., 2016). Looking at the USA, specifically, 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.[1] Even while the American Society for Bioethics and Humanities (ASBH) – the dominant professional organization in US bioethics with approximately 2 000 members – has begun certifying clinical ethics consultants (ASBH, 2020), the vast majority of HEC members would not consider themselves professional clinical ethicists. Thus, most of them may find themselves uncomfortable in the role as a "go-to" person for ethical concerns in the hospital. The present volume aims at reducing that discomfort by helping prepare HEC members for the challenges they are likely to face in this role.

[1] These numbers, while rough estimates, are supported by surveys by Fox et al. (2007, 2021).

Three Functions of HECs

As developed by the President's Commission, there has come to be a traditional threefold mission of an HEC. The most visible and often controversial role is to provide case review or, as it is often referenced, 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 of Conrad at the beginning of this chapter presses on 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 or patient access, and it might be asked to provide staff with further education about the ethical and legal considerations of family and other involved persons. We have devoted a section of this book to each of these topics, and, thus, will only briefly discuss them here.

Function 1: Case Consultation

Ethics is a specialty discipline with its own domain of inquiry. It leads to the development of moral norms and a deliberation of values in light of those norms. Thus, when an acute *ethical* problem arises in clinical care, turning to individuals with special education and/or experience to address it is akin to consulting a cardiologist when the patient has heart-related medical concerns. This explains 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 and/or mediating 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 7 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 (Smith et al., 2004).

1. **Individual Consultant:** Available in many large institutions or health systems with deep resources, individuals with trained expertise (and now, even certification) can serve as the primary ethics consultant. The individual's training typically consists of education in healthcare ethics (formally or informally) often supplemented with demonstrated competence in an academic discipline that informs the field (such as philosophy or religion), as well as familiarity with the clinical setting. In addition to the training, the individual consulting model has the benefit of expediency and flexibility, with a single person who is able to respond quickly to a request for help and meet with key individuals in an efficient manner.
2. **Multidisciplinary (aka "Whole" HEC) Committee:** An older model that remains common in smaller hospitals is that of a multidisciplinary committee that conducts consultations. A multidisciplinary committee ensures a variety of ethical and professional perspectives and gathers partial expertise from a larger number of individuals. This approach mitigates the lack of strong expertise in ethics through the use of multiple perspectives, values, and voices. An important detriment to the use of committees for review is that they can be cumbersome to assemble on short notice to respond to a pressing ethical consultation. Additionally, patients and/or families may be overwhelmed by the presence of an entire committee during the consultation process.

3. **Consultation Subcommittee (aka "Team-Based" Approach):** The third, quite popular, approach across a wide range of hospitals involves the appointment of select members of an HEC onto a consultation subcommittee. Members of the group are chosen for their special abilities and training in ethics and agree to be available to provide help when consults arise. This 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. An HEC should consider carefully which model best suits the institution and provide specific support for the chosen model in order to help it succeed.

As noted above, ASBH has developed a credentialing process, the Healthcare Ethics Consultant-Certified Program, as a way of professionalizing the practice of providing clinical ethics consults. This program requires individuals to get hundreds of hours of ethics-related experiences in the healthcare setting and then pass an exam. Earning the credential (an HEC-C) reflects endorsement of a minimum knowledge of key concepts and skills in healthcare ethics (ASBH, 2020). Because it only reflects basic competency, many people with certification would do well to work in teams and on ethics committees, rather than as solo consultants. This volume can provide some useful education for certification, but more importantly, it should help all members of an HEC be better prepared in the face of ethical challenges in the hospital.

Function 2: Policy Development, Review, and Implementation

Of the vast number of policies that each hospital creates, many policies deal with ethical concerns. Some have obvious ethical content, 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 clinical departments likely affected by the (proposed) policy. Policy work is some of the most important work undertaken by HECs: The very character of the hospital is expressed, in part, through its policies, and thus, 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. Per The Joint Commission, every institution must address "organizational ethics," but it remains an open question how much responsibility the HEC should take on regarding these issues. Yet ethics committees clearly have a role in addressing the organization's mission by offering reasonably clear guidelines for difficult situations: Good policies help individuals make good decisions and thus prevent some ethical problems from arising. They may also help to shape the institution's policies on workplace conduct, hiring practices, and the allocation of resources broadly construed.

Function 3: Education

Last but not least, the educational role of an HEC is twofold: looking internally at the HEC membership and externally at the institution's staff. As we have noted, the great majority of HEC members likely have little academic training or other formal background in healthcare ethics; 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

While some states and countries do have laws regarding some aspects of HEC work, most HECs do not operate under required legal or regulatory standards. Similarly, The Joint Commission fails to articulate expectations of an HEC (or even the processes by which ethics is addressed in the hospital). Thus, we can offer no definitive and authoritative guidelines about how the committee should be developed: its administrative location in the organizational structure of the institution, its charge, and its membership. However, we can provide some guidance based on considerations of the benefits a committee might bring to its institution.

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. There is no one single "home" for HECs. HECs have been created by the medical staff, by the hospital administration, and even some 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, developing the HEC as a medical staff committee intent on quality improvement, it may be easier to shield proceedings of the HEC from any potential legal scrutiny. Where the organized medical staff has yet to embrace fully the concept of an ethics committee, 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 placement of the HEC within the organizational structure requires careful thought. Determining the best place for an HEC to be "housed" within the organization will 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) often will become the de facto face of the committee and should be someone who enjoys respect and credibility among the many 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 their 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. Consider a co-chair model, as well; co-chairs can help gain credibility from different constituencies in the hospital, and they can share the workload in order to keep the committee moving forward, not getting stale. 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

Importantly, an ethics committee allows for an array of knowledge and perspectives to be brought to bear on consultation, education, and policy issues; otherwise, 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, chaplains, and ethicists). Second, a committee allows for a variety of expertise. Since general familiarity with ethical issues in health care 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 roles, 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 it legitimacy, and may enable resources to be allocated to the committee for education or other purposes that might otherwise be devoted elsewhere. It may be desirable to create ex officio (without voting privileges) positions for such roles, but 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 following the President's Commission's recommendations or structuring themselves after the institutional review board 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, member of a hospital advisory council, 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, even two, 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. While about a quarter of HECs require references and interviews to become a member, some have an expectation that members will also demonstrate character traits like integrity and honesty (Prince et al., 2017). Further, members must demonstrate a sincere belief 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 intent to do good and right with 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 by-laws should address size of the committee, terms of membership, frequency of meetings, and the scope of the three roles of consultation, policy review, and education.

HECs vary in size. One survey showed that larger hospitals (550 or more beds) can have over 30 members on the HEC, while smaller hospitals may have memberships as small as 10 persons. Further, length of service on the committee varies as well. About half of the HECs in the country have unlimited terms, while others have restricted terms as short as 1 year (Prince et al., 2017). 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 reasonable solution to the extremes is probably a compromise, such as staggered, fixed terms of several 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 mandated meetings are expected. While 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 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.

Ultimately, committee members should be encouraged to own each function of an HEC, and as such, 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 (having a budget for this purpose is highly desirable). Further, the bylaws might specify a base level of ethics education that committee members themselves should have.

With respect to policy review, the HEC should be charged to recommend changes up through 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, or a list should be kept as part of the HEC's standard processes and operations documents. 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, both in terms of what role it plays and outcomes to expect. An HEC may take on the consulting task itself or may provide oversight of a consulting service that is established separately from the committee itself. Further, although committees are typically charged only to make recommendations to others, some are in fact constituted (often through a specific policy) 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 a firm and ubiquitous 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 50 years, including several books and countless articles focused on the consultative function of an HEC. There are ethics committee networks in many states and regions of the country (Fausett et al., 2016). 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.

Questions for Discussion

1. Conceptual: How is the HEC viewed by staff, patients, and families in your institution? What challenging barriers and attitudes shape this view?
2. Pragmatic: Which of the three functions of an HEC present 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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