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## FROM THE EDITOR

### Health Care Ethics Consultation in the United States

#### Introduction

This issue of the *AMA Journal of Ethics* is devoted to the theme of health care ethics consultation in the United States, whether such consultation is performed individually or as part of the work of an organized committee. In recent decades, health care ethics consultation has become a permanent feature of the health care landscape. In 1983, when the first national conference on institutional ethics committees was held, a mere 1 percent of hospitals in the United States had ethics committees [1, 2]. Only 24 years later, a national survey published in the *American Journal of Bioethics* showed that all hospitals with more than 400 beds, all members of the Council of Teaching Hospitals, and all federal hospitals had a formal process in place for ethics consultation [3]. Clearly, health care ethics consultation in the United States has experienced very rapid growth, and our hope is that this issue of the *AMA Journal of Ethics* will provide physicians, medical students, and other health care professionals with insight into a service that has become an almost ubiquitous presence in health care practice. What follows is a brief overview of the role of ethics-related health care entities today.

#### The Role of Health Care Ethics Committees (HCECs)

Broadly, the functional role of any HCEC is threefold [4]. First, HCECs serve as a consultation resource to help clinicians, patients, patients' loved ones, and other stakeholders identify, analyze, and resolve ethically complex issues in clinical practice. Second, they provide continuing ethics education to members of health care institutions and more specialized training to members of the ethics committee itself. Third, most HCECs are involved in institutional policy formation and review in an effort to maintain and improve ethical treatment of patients on a systems level and—insofar as possible—reduce the need for ethics consultation and conflict resolution in the future. Ideally, these three functions complement each other. In order to better understand the role of ethics committees, however, it is useful to highlight how they differ from other institutional resources—particularly institutional review boards (IRBs) and palliative care services—and to distinguish between adult and pediatric ethics consultation services, as there are important differences that merit discussion.

#### Health Care Ethics Committees and Institutional Review Boards

HCECs differ from IRBs in both their historical development and their function. Following the infamous US Public Health Service *Syphilis Study at Tuskegee* (exposed by Jean Heller in 1972 [5]) and a series of other abusive research practices (exposed largely by Henry Beecher's 1966 article in the *New England Journal of Medicine* [6]), the National Research Service Award Act of 1974 [7] established a mandate for IRBs to monitor research

involving human subjects. IRBs, which are governed by title 45 of the Code of Federal Regulations (CFR), part 46 [8], are required for all institutions engaging in federally funded research involving human subjects. Although it could be argued that health care ethics committees also developed in response to a few widely publicized cases [9], their presence in US health care organizations has never been federally mandated. To date, only health care organizations seeking accreditation through the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) are required to have a “mechanism” for addressing ethical conflicts, and what this term means is not actually specified [9]. There is, therefore, a substantial difference between the regulation of IRBs and HCECs.

Their functional differences will become apparent to readers of this issue. Briefly, although both IRBs and HCECs promote the protection and rights of persons, IRBs are intended to safeguard the moral underpinnings of scientific research to ensure that, at a minimum, the ethical principles outlined in the Belmont Report (respect for persons, beneficence, justice) [10] and codified in the CFR (in, e.g., the requirement for informed consent) are upheld. HCECs, however, deal with a much more varied and less narrowly defined spectrum of ethical complexities arising not from research but from a wide variety of clinical scenarios and encounters. For HCECs, it is not enough simply to ensure that proper procedures for informed consent have been followed, for example, because this standard—while a *necessary* condition for most research and procedures done in health care contexts—is not *sufficient* to ensure that the principle of respect for persons has been honored.

### **Health Care Ethics Committees and Palliative Care Services**

Palliative care programs are a growing presence in health care. Palliative care strives to manage pain, incorporate psychosocial and spiritual care, identify values of patients and their loved ones, and resolve conflicts in cases in which the patient is terminally ill [9]. In 2000, only 24.5 percent of hospitals with more than 50 beds reported having a palliative care program; the proportion rose to 72.3 percent in 2013 [11]. Due to their shared clinical, rather than research-oriented, focus, HCECs and palliative care services have more of a functional overlap than do HCECs and IRBs. However, the *range* of cases handled by palliative care is much narrower than that of health care ethics consultation [9]. Whereas palliative care cases almost always involve patients with a limited life expectancy, cases referred for health care ethics consultations involve, in addition to terminal illness, ethical issues pertaining to the entire spectrum of clinical medicine. On the other hand, palliative care has a clinical focus that is much broader than that of ethics committees because it is concerned with so many aspects of a patient’s care, such as pain management [9]. Understanding this difference is helpful for health care practitioners, as it can help them determine which service would be more likely to meet the goals of patients, their loved ones, and members of clinical care teams.

## **Distinguishing Adult from Pediatric Ethics Committees**

In health care, it is well known that children should not be viewed as “just little adults.” This maxim is as true in an ethical sense as it is in a clinical one. Ethical issues involving children present layers of complexity that don’t always arise in adult cases. These include issues of informed consent or refusal by children’s guardians, assent from children, confidentiality, beginning-of-life care, and the myriad ethically and psychologically complex issues that accompany death and dying in children. One retrospective survey, for example, found that the most frequent topic leading to a pediatric ethics consultation was end-of-life issues [12]. Surprisingly, despite the particular complexity of pediatric ethics cases, pediatric ethics committees have developed more slowly than adult ethics committees [13]. In some organizations, one consultation service handles cases pertaining to both adults and children.

Nevertheless, it behooves health care professionals to be aware of relevant differences in the nature and scope of pediatric and adult ethics cases. If it is indeed true that health care ethics committees can help improve the quality of patient care [14, 15], we might reasonably hope that an increasing number of organizations with the capabilities for acute inpatient care of critically ill children will be able to provide these children, their families, and their clinicians with appropriately specialized health care ethics consultation.

## **Summary**

HCEC services perform a distinct role in modern health care institutions. Fundamentally, their roles are to (1) clarify ethical values and aid in conflict resolution, (2) provide ethics education, and (3) make and review institutional policy. As with IRBs, the guiding framework for ethics committees is constituted by the principles of medical ethics, which were first described in the Belmont Report as respect for persons, beneficence, and justice [9]. The function of ethics committees extends beyond that of IRBs, which are principally concerned with research ethics and compliance with federal regulations. While palliative care services deal with medical and goals-of-care issues at the end of life, HCECs are called upon to identify, analyze, and help in the resolution of ethical conflicts in cases involving patients at all stages of life. Some institutions find it useful to have separate pediatric and adult ethics committees because of the unique issues arising with these different patient populations. Our goal in this issue is to articulate for the reader some of the current issues regarding HCECs, with the hope that improved understanding of HCECs will lead to more effective and appropriate use of their services in clinical care.

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## ETHICS CASE

### What is an Emergency Ethics Consultation?

Commentary by Jeremy R. Simon, MD, PhD

Dr. Rodriguez is an emergency medicine physician at a large, urban hospital. It was a Tuesday evening and the day had been relatively calm. At 6:30 p.m. she admitted an unconscious male who had been airlifted by emergency services from his home in a rural region 200 miles from the city.

Upon assessing the man, she noted that he had markedly shallow and infrequent respirations. She was informed that he was found, unconscious, in the bathroom with an empty bottle of barbiturates on the floor. He had been found with a do-not-resuscitate (DNR) form and a hand-written letter stuffed in one of his pockets, in which he detailed his belief in rational suicide. The form and the letter had been discovered en route to the hospital by the paramedics. Of note, the man's daughter—who had found him and called emergency services—had informed them that they should disregard any DNR order he had "on file" because she was under the impression that he had been depressed. Upon hearing this, Dr. Rodriguez quickly read the letter that had been found with the patient. In this letter, the man listed his psychiatrist's phone number, so Dr. Rodriguez decided to call him to try to get more information.

Upon reaching him, she learned that four years ago the patient had come in to see the psychiatrist at the request of his daughter. The patient suffered from a progressive neurodegenerative disease and had a morbid fear of crippling disability and pain; he had informed his daughter that, should his disease progress to a point at which his quality of life became unacceptable to him, he would consider killing himself. His daughter had found this very disconcerting, leading her to request that he see a psychiatrist before deciding about the DNR. At the time the psychiatrist felt that he was not acutely suicidal but was simply expressing his belief in rational suicide. The psychiatrist felt he had capacity and that depression was not playing a role in his decision about his DNR status.

Normally, Dr. Rodriguez would have intubated the patient immediately; however, this discussion and the DNR order and letter made her pause. The daughter, who was the only other source of information on the patient, had not yet arrived at the hospital. The patient, on the other hand, was rapidly progressing towards respiratory failure and death. Dr. Rodriguez decided to call the director of the adult ethics committee at her institution for an emergency ethics consultation. She explained to him what she knew, recounting her conversation with the psychiatrist and confirming that there were no

family members present with whom to discuss the patient's status and care plan. She also explained that she needed to make a decision quickly because of how rapidly the patient was progressing to respiratory failure. After making sure he understood all the details Dr. Rodriguez had communicated to him, the director of the ethics committee reasoned that, because the DNR order had been signed in the setting of a progressively disabling neurodegenerative disease—in addition to the fact that the patient had been [screened for depression](#) before and also had a documented belief in rational suicide—Dr. Rodriguez could refrain from beginning invasive resuscitative measures. After deliberating for as long as she thought she could, Dr. Rodriguez decided this course of action was in the patient's best interest and did not intubate him. Half an hour later the patient died.

An hour later the daughter of the deceased patient arrived at the hospital. Upon learning of her father's death, she became extremely upset. She informed Dr. Rodriguez that her father had advanced multiple sclerosis (MS), which had been causing him increasing pain over the years. Four years ago he had inquired about a DNR form, and, after hearing that he believed suicide to be an option if his disease progressed beyond what he wanted to live with, she had wanted him seen by a psychiatrist for possible depression. The psychiatrist felt he was not depressed and that he had capacity to decide about a DNR order. However, she insisted that her father had not been "the same since he last went to the psychiatrist." Her father's younger brother, with whom he had a close relationship, had died suddenly of a heart attack two months ago. Although her father had not sought help with his grief since his brother's death, she reported that he had been "acting depressed" and that this had caused her to be worried for him. She started checking in on him every evening after work, which is how she found him. She argued that his DNR status was no longer valid because the context in which her father had made that decision had changed significantly due to the recent death of his brother—he now wanted to take his life because of his acute depression rather than because of his progressive neurological condition. Furthermore, she was upset that her explicit instructions to attempt resuscitation despite his DNR status had been ignored.

Dr. Rodriguez explained that it had been a difficult decision. She also explained that she had consulted with the chair of her hospital's ethics committee. Upon learning this, the daughter became even more upset, accusing Dr. Rodriguez of justifying her "inaction" on account of a "short conversation with someone who knew nothing" about her father. She was firmly of the opinion that, because of its urgency, the ethics consultation that had taken place was not a valid ethics consultation at all. "What is the value of an ethics consultation if the family and friends aren't even consulted? I have to live with the consequences of this decision and my input wasn't considered ethically relevant?"

## Commentary

As is the case in most of medicine, even [emergency medicine](#), few matters are actual emergencies. Nonetheless, all clinicians must be prepared for those emergencies they might encounter, ethics consultants included.

If we are to discuss emergency ethics consultation, it would be useful to begin with a working definition, or at least a general understanding, of what constitutes an emergency in this context. For our purposes, we can characterize an emergency as a case in which one must act promptly and, because of that time constraint, potentially without the information or tools one would use under ordinary circumstances.

There are a few things to notice about this definition. First, not all emergencies will necessarily occur, start to finish, within a short time frame. A case can start out ordinary, with seemingly adequate time for deliberation, but, as the initially reasonable deadline for a decision draws near and one still does not have all of the information (or tools) one would like to have, an ordinary case can turn into an emergency. This is not surprising, as all cases have background; most emergencies, whether avoidable or not, often start as something less obviously concerning. It is only as matters reach a crisis that a case becomes an emergency, and ethics consultations are no different. Second, this definition does not necessarily apply to all clinical uses of the word “emergency.” Thus, one could plausibly describe emergency surgery as surgery that must occur before there would otherwise be an opening in the operating room schedule, even if one has all the information, tools, and (momentary) patient stability one would ordinarily want for surgery. Nor is it the same as the meaning of the word implicit in the practice of emergency medicine, where an emergency is whatever a patient thinks is an emergency.

As I said at the beginning, one must be prepared for emergencies. The first step in preparation, at least logically, is being able to recognize an emergency. To make the above definition less abstract, we can say that an ethics consultation is an emergency when we do not yet have all the ethically relevant information we would want, the question concerns a medical decision that must be made promptly or the opportunity to choose among courses of action will be closed off, and, whatever course one chooses, the decision is irreversible.

Each of [these conditions](#) eliminates some cases that might be perceived to create an ethics emergency. If all of the data and interested parties are present, then, although we might have to act fast, there is no true emergency, at least not in the sense that the case must be handled in a special way. Second, if the urgency is driven not by an impending change in the patient’s clinical situation, but rather by the staff’s perception that “it’s time to make a decision” and waiting for all the ethically relevant pieces to fall into place will “take too long,” there likewise is no ethics emergency—at least assuming the pieces would fall into place in a reasonable length of time, even if staff does not want to wait. A

“reasonable length of time” does not have a fixed value but is relative to the situation at hand. In an emergency department, where events occur on the order of minutes to hours, waiting two days to make a decision is not reasonable. Waiting two hours can be. On the other hand, on an inpatient service, waiting two days, or maybe even two weeks, would be reasonable though waiting two months likely is not. Finally, the third condition suggests that if the irreversible decision can be deferred, there is no ethics emergency, even if an apparently important decision must be made. Thus, if there is a question whether to intubate an elderly patient with impending respiratory failure due to pneumonia and the patient’s health care proxy is not available, one would probably intubate the patient. If the proxy determines that the patient should not have been intubated, the patient can then be extubated and allowed to die of respiratory failure. Of course, in this latter case, an ethics consultant may need to respond emergently, because the clinical team needs to act and may not know the right thing to do, but there is no true ethics emergency, as the irreversible decision can be effectively deferred.

The case presented would, it seems, be an emergency. Since Dr. Rodriguez knew the daughter objected to honoring the DNR order but initially did not know why, there is certainly missing information here. Second, as subsequent events make clear, there was little time to intubate the patient if Dr. Rodriguez was to save him; she could not necessarily wait for the daughter to arrive. Finally, a decision to intubate may not be reversible. Unlike pneumonia in an elderly person, whose severe respiratory distress will likely last for a while, even after intubation, respiratory failure as a result of overdose may be transient. After a few hours, the patient may regain the ability to breathe on his own, and reversing the intubation will not return us to the point we were at before we intubated. If our goal was to allow the patient to die, we will have lost our opportunity. Therefore, just as a decision not to intubate would be irreversible, leading to the patient’s death, a decision *to* intubate might also be irreversible, leading to the patient’s living even if the patient is extubated soon thereafter at the request of the surrogate. If the proper decision from an ethical perspective would have been not to intubate the patient and let him die, then, ethically, his living would be the wrong outcome. (We should note here that the question of [honoring advance directives](#), including DNR and do-not-intubate (DNI) orders, is—in cases of attempted suicide—a difficult issue on which there is not clear consensus. I will not engage this question in this discussion, but instead assume that not intubating this patient is at least possibly appropriate.)

Having identified this case as an emergency, the question is how to proceed with an ethics consultation. In some cases, the approach, at least from a technical perspective, is straightforward. If the problem is that the case’s urgency means that some information cannot be obtained or some people (in this case, the patient’s daughter) not spoken to before a decision must be made, then one must make a decision with the information one has using the usual principles of medical ethics decision making. No decisions, even nonemergent ones, are made with perfect information, and even many medical ethics

cases with no time pressures need to be decided with information missing. In some cases, as, apparently, the one presented here, proceeding with the information available may mean proceeding without talking to some of those who have an interest, if perhaps not a say, in the outcome. When time is short, there may be no other option.

Sometimes, however, the problem will be a relative, not absolute, lack of information. That is, there is no information that is inaccessible, but there is not time to gather all the information one would want. In this case, one must prioritize and decide which questions to ask and whom to speak to. There is, of course, no rule to guide a consultant about where to turn first and which pieces of the story to defer gathering, with the understanding that deferring could turn into ignoring. Each case will be different. A consultant needs to have the ability to quickly assess a case, identify the key ethical and clinical factors, apply the relevant ethical knowledge, and respond quickly and decisively. To a certain extent, these skills are matters of experience and temperament, but they can also be taught. Just as emergency physicians learn how to approach neurological, cardiac, and surgical emergencies, ethics consultants can learn to quickly identify key features of various types of cases. But just as the parts of the physical exam that can be skipped in a neurological emergency differ from those that can be skipped in a patient with an abdominal surgical catastrophe, different ethics questions demand that different key parts of the medical and social history take priority. There is no fixed template.

Regardless of the nature of the missing information, when doing an emergency consultation, one must be prepared for potential further developments. In this case, the ethics consultant should have anticipated the arrival and possible responses of family members and others who were not present to contribute to the discussion when the decision was made. Even when family members do not have decision-making authority for a patient, they have an important role in ethics consultations. First, they may have important information, as did the daughter here regarding her father's possible recent depression. Equally important, decisions made in ethics consultations, especially regarding removal or withholding of life-sustaining treatment, can have a profound impact on the family. Even if the decision made is not the one a family member would have wanted, participation in the process, being present for the appropriate discussions, can be valuable, allowing the family members to feel heard and to understand and come to terms with the decision.

In emergency cases, however, family members might not have the opportunity to participate as they might want to, and this can lead to conflicts, as this case demonstrates. Anticipating this problem will assist an ethics consultant and/or treating clinician in helping the family members understand and accept the outcome, even if the family objected to it. In this case, Dr. Rodriguez knew the patient's daughter wanted him intubated (based on her request to ignore the DNR order). Dr. Rodriguez could have been prepared to make clear that her goal was to act in the patient's best interests, and that a

decision had to be made promptly, with the information at hand. She could also make clear that of course the daughter's input would have been valuable, but that, given the circumstances of the case, it was not possible to wait for her while still acting in what seemed to be the patient's best interests. This is not to say that such approaches will always completely resolve all these conflicts. However, given that the treating physician and consultant may be faced with quick, strong, reactions from the late-arriving family, anticipation will allow them to deal with this in the most constructive and compassionate manner possible.

Another type of further development one should be prepared for is further information that indicates one may have made the "wrong" decision—wrong not in the sense that one should *in fact* have decided otherwise, but in the sense that, had this information been available at the time the decision was made, one would have decided otherwise. In this case, the fact that the patient may have recently been depressed calls into question the determination that this was an act of rational suicide, even though the patient believes in rational suicide in general. Had the clinicians and consultants known of this depression, the consultant might have advised Dr. Rodriguez to intubate the patient. However, decisions can only be made based on the information available at the time of the decision; later revelations do not make an earlier decision wrong, and one should not feel one has made a mistake. Only if the information available at the time was not gathered and acted on appropriately can a decision truly be considered wrong.

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## ETHICS CASE

### Process Matters: Notes on Bioethics Consultation

Commentary by Hannah I. Lipman, MD, MS, and Tia Powell, MD

Mrs. Ludford, a 48-year-old mother of two, has been in the care of a Connecticut nursing home for the past five years. A passionate horseback rider, she was thrown from a horse while crossing a creek at the age of 43. She hit her head on a rock and was partially submerged in the creek's water for approximately 15 minutes before her riding partner found her. She was diagnosed by at least three different neurologists as being in a persistent vegetative state (PVS) due to severe hypoxic brain damage. Over the years, despite good care, she had developed numerous complications: repeated pulmonary, urine, and skin infections and a decubitus ulcer. Most recently, she had developed what was suspected to be a massive stroke, for which she had been hospitalized in the intensive care unit (ICU) of a nearby medical center. There was no way to assess the extent of damage caused by the stroke due to her inability to undergo neurological exams while in PVS.

Her neurologist felt that the likelihood of Mrs. Ludford emerging from PVS after five years was slim to none. In addition to this assessment, the nurses taking care of the patient at her home facility expressed their frustration about having to care for a woman whom they felt was being maintained in a "living death" for what seemed like an indefinite period of time. It was the unanimous opinion of the care team that Mrs. Ludford's needs were not best met in an intensive medical environment and that she should be referred to a palliative care service for comfort care.

The patient's husband and two children—both of whom were now adults—had always insisted that the patient be treated aggressively to keep her alive as long as possible, regardless of her neurologic state. They had repeatedly expressed to the medical care team that they wanted everything to be done for her, "no matter how much it costs." When the option of transferring Mrs. Ludford to palliative care was discussed with the family, they became extremely upset. They expressed a feeling of betrayal at the fact that the institution and the medical team responsible for their mother's care were "giving up." They considered transferring her to a different organization, but because she was too medically unstable, this was not an option. Thereafter the family refused to talk to her doctors. They threatened legal action if the hospital withheld or withdrew aggressive acute care.

An ethics consultant became involved at the request of Mrs. Ludford's physicians, in hopes that she could facilitate communication between the caregivers and family members. However, upon learning that several of the hospital's physicians were members of the ethics committee, the family members became wary of the ethics consultant. They eventually decided that they did not want to discuss the matter with the ethics consultant and refused to meet with or talk to anyone associated with the ethics committee. Some physicians saw this refusal as a way of stalemating the process and thus forcing Mrs. Ludford's medical care to continue; others, including members of the ethics committee, saw it as an understandable reaction given the family's mistrust of the hospital. There was disagreement among members of the ethics committee as to whether the committee should remain involved in the case.

### **Commentary**

In [bioethics consultation](#), process matters. How we gather information and manage relationships makes a difference to the outcome. The ethics consultant (or team) must follow a standardized process and carefully heed stakeholders' voices. Doing so helps promote the values of the patient, clarifies ethically justifiable options, facilitates acceptance and implementation of a resolution, and stimulates the education of all involved. The case of Mrs. Ludford and her family demonstrates a missed opportunity for bioethics consultation to bring together those caring for the patient with those who love her.

### **Process Starts at the First Contact**

Process matters from the first contact with the requester, for it sets the tone for all that follows. The bioethics consultant should (1) clarify the ethics question and other issues in the case, listening carefully to the requester to understand the sources of ethical complexity or conflict, which might be difficult for the requester to articulate; (2) [identify and include](#) stakeholders in deliberations; (3) inquire how the requester hopes a bioethics consultation will help; and (4) uncover and address any misconceptions about the bioethics consultant's role [1]. Furthermore, ethical issues are often only one source of complexity or conflict in a multifaceted case involving practical, clinical, psychosocial, legal, and other features. The consultant should clarify the nature, scope, and role of the bioethics team while connecting the requester with other appropriate resources when necessary [2].

Common misconceptions about bioethics consultation or consultants are that they can [protect clinicians from litigation](#), substitute for the clinical team in breaking bad news, or quickly endorse the team's preferred plan without engaging in a thorough analysis of the ethical issues [1]. Particularly with conflicts about what the [goals of care](#) should be, a requester might hope to enlist the bioethics consultant as an ally against other stakeholders. The consultant must explain that a good conflict resolution process

includes considering stakeholders' perspectives, promoting dialogue, and facilitating consensus.

After speaking with the requester, the bioethics consultant gathers information from the patient's health record and other stakeholders, including the patient's family and clinicians. The consultant should approach each subsequent conversation in a similar fashion and listen carefully, clarify the role of bioethics, and address any misconceptions. It is also crucial to spend time with the patient, including those patients who are unable to express their own perspectives and values. Secondhand impressions are no substitute for observing the actual person at the center of a clinically and ethically complex dilemma [3, 4].

### **Sensitivity to Language as a Tool of Bioethics Consultation**

Many cases referred for bioethics consultations involve a breakdown in communication. Relying on basic communication skills, such as listening attentively and communicating in a precise and empathic fashion, a bioethics consultant permits stakeholders to share anger, sorrow, and other emotions; ask questions; and articulate concerns. The consultant notes how each stakeholder frames the case or conflict; a person's words reveal clues about their values and goals and illuminate different perspectives on the conflict. Telling one's story and feeling heard and respected can also facilitate collaboration.

In this case, the team's language has likely deepened the conflict. The family is characterized by the team as "stalemating the process and thus forcing Mrs. Ludford's medical care to continue." Life-prolonging interventions are often labeled "aggressive," as in the description of this case, while the alternative is described as ceasing care altogether. No wonder Mrs. Ludford's family concluded that the team was "giving up." In contrast, we learn almost nothing of the understanding, experience, or values of Mrs. Ludford or her family, suggesting that the team has not adequately attended to their perspectives.

*Responding to the clinical team's concerns.* Hearing this language, a skilled bioethics consultant would acknowledge the team's frustration and concerns but communicate that the role of bioethics is not to help extract an agreement from the family to stop medical care for someone they love. Mrs. Ludford and her family deserve medical care. Reasonable people can debate what constitutes optimal goals of that care (comfort, life prolongation, minimizing burden to family, and others), but the presence of an ethical obligation to provide care for Mrs. Ludford and her family stands beyond question.

*Responding to the family's concerns.* It is unclear how Mrs. Ludford's family members learned about the bioethics consultation and whether they were introduced directly to any members of the consultation team. However they learned of the consultation, it

increased rather than decreased distrust, which means this crucial step in the consultation process failed. The family mistrusts the bioethics consultation team because it includes some hospital physicians. Our experience has been that listening to and valuing family members' perspectives, as well as visiting the patient and demonstrating respect for her as a person, helps build trust. Bioethics consultants should acknowledge that they are hospital employees but stress that they promote the interests of both the hospital and the family by helping them find common ground.

### **Stating the Ethics Question**

Framing clear ethics questions helps stakeholders better understand the problem and the values at stake and ensures that the consultant is addressing the issues that prompted the request for help [1]. In this case, possible ethics questions include the following:

1. Given Mrs. Ludford's poor prognosis for recovery to her baseline level of function, is it appropriate to offer intensive care?
2. Given Mrs. Ludford's poor baseline level of function, is life prolongation an appropriate goal of treatment?
3. How can conflict between the ICU team and Mrs. Ludford's family be addressed in order to optimize shared decision making and negotiate achievable goals of care?
4. Under which circumstances is it ethically justifiable for the clinical team not to offer a particular treatment or intervention, even if Mrs. Ludford's family demands it?
5. What are the clinical team's obligations to Mrs. Ludford's family, even if agreement is not reached on goals of care?

Any of these questions might apply, depending on Mrs. Ludford's current clinical status and prognosis.

### **Choosing an Intervention**

Three tools available to a bioethics consultant in this case include mediation, clarifying policy, and coaching the team on communication strategies. Finding an appropriate strategy depends on the nature of the ethics question. This case, at heart, reveals a breakdown in shared decision making and conflict over what are [appropriate, achievable goals of care](#). In the case presentation, the focus is on conflict about specific interventions—ICU care, life-prolonging treatment, and transfer to the palliative care service. But what is at stake, really, is which goals those interventions can realistically achieve and whether those goals are appropriate. This case also raises questions about the appropriate roles for the team and family members in shared decision making, especially if the family continues to pursue clinical outcomes the team finds unrealistic.

*Mediation.* [Mediation](#) can often help resolve conflicts over goals of care by bringing the involved parties to consensus around an ethically justifiable plan [4]. Even if consensus is

not reached, facilitated dialogue improves shared decision making and builds trust. A clinical team can gain appreciation for a family's understanding, experience, goals, and values, and for who the patient is as a person. A family can gain understanding about the patient's prognosis, treatment options, and the benefits and burdens of each option. Unfortunately, Mrs. Ludford's family members decline to participate and forgo opportunities to voice their perspectives and concerns during a meeting. We cannot be sure, but it seems that inattention to process helped derail this consultation. The bioethics consultant should try to forge a relationship with Mrs. Ludford's family, but the level of mistrust could prevent this.

*Clarification of policy.* Policy clarification is another way for bioethics to help a team and does not require cooperation from a patient's family. The hospital in this case might have two policies that deserve consideration: for example, one delineating how ICU triage decisions are made and another guiding clinicians in so-called "futility" conflicts. However, merely clarifying organizational policies does not substitute for the mediation process described above and is unlikely to address the ethics questions raised in this case. An ICU triage policy, for example, might delineate limits to surrogate authority over decisions about where care is provided, and a "futility" policy might outline processes for transferring patients when attempts to resolve conflict fail. Relying on such clauses to bypass the work of building relationships with families would be a missed opportunity, however. Moreover, clinicians' obligations to support and demonstrate respect for family members of critically ill patients, even when their goals are unrealistic, would go unfulfilled.

*Communication coaching.* Coaching is another tool that might help communication in this case. Even without the participation of Mrs. Ludford's family, the consultant can counsel the team about communicating with the family to improve their relationship, build trust, and enhance shared decision making. [5] For instance, the team could ask Mr. Ludford and the children to share stories about Mrs. Ludford and how her accident has changed their lives. Doing so demonstrates respect for the patient as a person and signals willingness to listen, and not just talk [4].

The bioethics consultant should urge the team members to clarify and communicate clearly what they know and don't know about Mrs. Ludford's prognosis. Prognosis is a crucial factor in determining what goals each treatment option can achieve and for distinguishing interventions that are only harmful and need not be offered from those that are subjects of disagreement about appropriate goals. If Mrs. Ludford is dying regardless of treatment, irrespective of whether or not she remains in the ICU, perhaps the team should set aside the discussion about interventions and focus on support for the grieving family members.

If, on the other hand, Mrs. Ludford's prognosis could include a return to her baseline level of function, the team should explore what Mrs. Ludford would consider a life worth living. By assisting her family in applying these values to decisions, the team could lay a foundation for negotiating realistic goals of care. In any case, productive discussion requires clear information about prognosis and the potential benefits and burdens of each treatment option.

### **Recommendations**

Given that the perspectives of important stakeholders—namely, Mrs. Ludford and her family members—are missing, the consultant here can only give general guidance to the team about process. No recommendation predicated upon case specific information is appropriate without incorporating the family members' perspectives into any plan. Given the lopsided nature of stakeholder participation in this case, we would avoid recommending for or against unilateral withdrawal of life-sustaining treatment, for this would be to "side" with one party in the conflict.

### **Addressing Moral Distress Among Clinicians and Identifying Systems Issues**

Moral distress occurs when clinicians find they are prevented from providing what they believe to be the right care for a patient. Mrs. Ludford's nurses described her life as a "living death," suggesting they experienced considerable moral distress. A bioethics consultant could offer to meet with distressed clinicians, creating a forum to share concerns [6]. The consultant also identifies systems issues, which should be addressed through institutional policy or education. In this case, the consultant might identify educational needs about best practices for ethics consultation and communication.

### **Documentation**

The final step in a bioethics consultation is to document the consultation—including background information, ethics questions, recommendations, and analysis supporting those recommendations. A clear note in a patient's health record can educate clinical teams about common ethics issues, bring the voices and perspectives of patients and families into the health record, and document how the bioethics consultation process impacted the patient's plan of care [7].

### **Conclusion: Educating Bioethics Consultants**

Bioethics consultation is an evolving and relatively new field. Practice varies widely. Unfortunately, not all who perform consultations have pursued relevant education, although opportunities for consultation training are increasing. The American Society for Bioethics and Humanities (ASBH) is developing standards for consultation competence and is piloting a method of assessing individual consultants [8]. Did this particular consultation process break down because of a lack of skill and training? It is impossible to know. Certainly the need for bioethics consultations can arise when communications between clinicians and families fail, as in this case. Unfortunately, whether due to a lack

of attention to process or too deep a well of mistrust, consultants in this case might not be able to repair the rift. Still, even when family members decline to meet with bioethics consultants, we can coach colleagues, educate stakeholders about policy and communication, and work toward providing ethically robust health care.

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## ETHICS CASE

### **Consequences for Patients and Their Loved Ones When Physicians Refuse to Participate in Ethics Consultation Processes**

Commentary by David S. Seres, MD, ScM

Sarah is a 17-year-old girl currently in the intensive care unit (ICU) of a large academic medical institution. She was diagnosed with an aggressive soft-tissue sarcoma a few years ago and has been receiving treatment from her oncologist, Dr. Hunter, who is a senior member of his department at the institution. Despite Dr. Hunter's best efforts and Sarah's participation in multiple experimental therapies, she has been getting progressively worse and is now visibly cachectic and in pain. Dr. Hunter can think of no further conventional chemotherapy options.

Sarah's parents are very concerned for their daughter's well-being, and they have for many years generously donated to the institution's oncology department. Over the years they have also formed a close relationship with Dr. Hunter.

The ICU physicians taking care of Sarah during her current admission determine her cancer to be at a very advanced stage, with imaging confirming metastatic lesions in her lungs, liver, and bones. Due to her progressive wasting and pain, they feel that comfort care is indicated. However, when this option is discussed with Sarah's parents, they say that this is absolutely not an option for them. Following this tense interaction, it becomes clear to the medical care team that Sarah's parents only trust Dr. Hunter and will not consider options discussed with them by other clinicians.

The house staff contacts Dr. Hunter to communicate their impression that Sarah should be transferred to palliative care, hoping that he will be willing to discuss the transfer with the family. To their surprise, Dr. Hunter disagrees, telling the house staff that "we need to make sure her parents feel like we took care of her until the very end." Dr. Hunter also argues that the longer the house staff is able to keep Sarah alive, the more likely it is that an unconventional therapy option might present itself. He refuses to discuss the option of palliative care with the family.

When this situation is discussed the following day during multidisciplinary rounds, one of the ICU nurses tells the team that she knows Dr. Hunter has a close personal relationship with Sarah's parents. She also informs the medical care team that the parents are known benefactors of the institution's oncology department. After confirming these claims, the house staff feels that Dr. Hunter's financial and personal ties to the family are clouding

his judgment—and, as a result, negatively influencing Sarah’s medical care. They initially hesitate to call for an ethics consultation because Dr. Hunter is such a powerful and well-respected figure at the institution. Ultimately, however, they call for an ethics consultation because they strongly feel that Sarah’s current medical care is [inappropriate](#).

The hospital’s ethics committee requests Dr. Hunter to appear before the committee in order to discuss the potential conflicts of interest he might have in the case. However, Dr. Hunter refuses to do so, arguing that he never called for an ethics consultation and is under no obligation to participate. He also argues that, even if *he* had called for an ethics consultation, he would be under no obligation to share the committee’s recommendation with the family if he disagreed with it, much less convince them that this was in Sarah’s best interest.

### **Commentary**

Sarah’s case illustrates multiple dilemmas related to the function and [role](#) of an ethics committee (EC), including the means by which the EC interacts with members of the clinical team, the authority of the EC, and the impact of the patient’s family’s status as institutional benefactors on clinicians’ decision making or EC members’ recommendations. The case hinges on Dr. Hunter’s unwillingness to participate in the ethics deliberation process and includes concerns about possible conflict of interest.

### **Structural Roles in Ethics Committees**

Often, the structure of an EC includes a clinical ethics consultation team (or an individual consultant) and a larger deliberative body. The former should, of course, be highly skilled at performing ethics consultations. Standardization and credentialing for clinical ethics consultants is being discussed at a national level, and health care organizations should establish policies to determine who is allowed to perform ethics consultations [1].

*The consultants.* Most ethics consultations are performed by an individual consultant or small subcommittee or team. The conversations are often quite intimate. Limiting the number of participants to prevent deliberations from feeling confrontational might be desirable, but consultants must also take care not to exclude stakeholders who can be substantially affected by decisions and outcomes of deliberations. The decision that the EC made to summon Dr. Hunter to appear before the committee might have contributed to or even caused Dr. Hunter’s refusal to participate. A request to appear before the EC has a punitive or confrontational feel, no matter the intent. Perhaps the family and Dr. Hunter had been approached multiple times about the issues raised in the ethics consultation and were therefore primed for a fight.

*The deliberative body.* The larger EC should function in a deliberative and advisory role and have a multidisciplinary membership that includes multiple clinical specialists, legal

experts, and administrators. Many deliberative bodies draw as well from members of the community and former patients or their family members. Clinical specialists represented might include medical practitioners, nurses, social workers, patient services representatives, spiritual care practitioners, and others, depending on specialists' availability, interest, and expertise. The EC should reach out broadly for membership, as practitioners in disciplines such as nutrition, physical therapy, occupational therapy, and speech pathology, to name a few, are frequently exposed to ethically challenging situations and can make excellent contributions to the EC.

It is advisable that the larger EC be given authority to present policy recommendations for adoption by the health care organization through the medical board or another administrative body. But it is critical that the EC not be seen as a punitive or authoritarian body. Ethics consultation is best performed as a consensus-building or facilitation process or as mediation [1].

In addition to setting policy, the larger EC is often very helpful in advising the consulting team about how to address complex or novel situations. A situation such as presented in our case, for example, might be brought by the consulting team to the full EC for advice, given the political complexities of the involvement of a powerful doctor and [donor family](#).

To be able to serve in the [role of intermediary](#), the EC and consultation teams must be known for impartiality and must serve in an advisory role. When consensus cannot be built, which is not infrequent, laws and policies might specify who should be allowed to be a decision maker. In these situations, the ethics consultation might only have the effect of reassuring a distraught medical staff that everything possible has been done to resolve clinical or ethical complexities.

### **How Should the Ethics Consultation Proceed in this Case?**

*Acknowledge staff members' [moral distress](#).* It is clear that this case has generated moral distress among some members of the staff. This is likely caused, in part, by medical orders to pursue treatment they find morally objectionable, which can seriously influence morale over the short and long term, and perhaps even patient care. Unresolved situations such as this create discord, necessitate staff shifting, and have even resulted in collective actions such as sick-outs (the taking of paid time off—"sick days"—for protest, in lieu of a formal strike). Another concern, judging by staff members' comments about Dr. Hunter's conflict of interest, is that Dr. Hunter appears to be seen by some as less trustworthy. When ignored, conflicts of interest tend to undermine trust in an organization or person and add to the urgency the EC might feel to resolve this situation. Moreover, assumptions about different stakeholders' motivations can be a source of bias, misunderstanding, and misperception that needs attention from an ethics perspective, too. Addressing these issues with the staff, perhaps in a meeting separate from the patient and family, is an important opportunity for the EC to try to influence the

culture and morale at the health care organization. While easily overlooked, this step should be of primary importance for the EC.

*Outreach to Dr. Hunter.* The EC in this case might be well served to look to its membership for someone with an existing relationship with Dr. Hunter and have that person reach out to him for a one-on-one conversation. The request should be couched in nonthreatening terms that avoid any hint that the EC has any intention of embarrassing or undermining Dr. Hunter or infringing on his relationship with Sarah or her family. Ideally, such a request should be made in a way that would appeal to the common ground between Dr. Hunter and the EC: a desire to do well by Sarah, her family, and the hospital. In this case, the consultation team might indicate to him both an awareness of escalating tensions surrounding Sarah's care and a desire to solicit his insights. The consultation team's offer to serve as intermediary to help avoid further conflict, rather than to push a decision-making agenda, should be explicit.

Further attempts at communication, as outlined below, are warranted.

*Address Dr. Hunter's intransigence.* Dr. Hunter's refusal to meet with the committee or consultation team might seem to present a significant barrier for the ethics consultant. Generally speaking, ethics consultation should be available at the request of anyone involved in the care of the patient, without regard to others' willingness to participate. For cases in which practitioners, family members, or even surrogate decision makers refuse to participate, ethics consultants should attempt to assess situations in which they're not yet involved while attempting to find creative ways to secure an invitation to become involved.

More challenging could be situations in which a primary physician attempts to block an ethics consultation or refuses to communicate the recommendations of the clinical ethics consultant to the patient or family, as Dr. Hunter has done. As mentioned, ethics consultation is available to everyone and so no one should be able to prevent others from accessing one. Ideally, these situations can be prevented by the EC positioning itself as a mediating, rather than punitive, body.

But once situations have arisen in which recommendations—or even the fact that an ethics consultation was requested—are kept from the patient or family or other key stakeholders, they should be dealt with on a case-by-case basis according to institutional policy. In general, a situation in which actual harm might come from withholding the findings of the EC should compel the overriding of the primary physician's refusal to divulge, and the EC might even be compelled to seek assistance from organizational leadership in communicating with the obstructing clinician. There is not enough information provided in this case to know whether there was a risk of harm from not divulging the EC's findings. One could imagine a similar situation in which a

young patient is disagreeing with her parents about goals of care, the choice to forgo further life-prolonging therapies is deemed reasonable by the EC, and the patient's choice might be respected if the EC could weigh in. But the EC must be circumspect in judging the value of its own recommendations. Again, an in-person, one-on-one, nonconfrontational approach to communicating with the primary physician is recommended in this situation.

*Address possible conflicts of interest and bias.* The donor status of the family should be considered as a potential source of bias in clinical and other types of decision making. Access to medical treatment should be equitable for all, regardless of patients' or their families' financial support of an organization. In this case, while the consequences might be significant and cannot be ignored, ethics consultation might be considered part of the medical care. The EC will have to take great care to act as it would in any other matter and avoid being inappropriately influenced by the family's donor status.

On the other hand, given the longevity of the relationship between Dr. Hunter and the family, his behavior might in fact express respect for the family's desires. Because his reaction takes the form of an unwillingness to meet with the team, the information that would allow assessment of his reasons is incomplete. There is a lack of evidence in this case; jumping to conclusions should be avoided. The assumption that his reaction stems from a conflict of interest could reflect a bias on the part of the staff or the EC. The EC should develop strategies for acknowledging and mitigating potential bias created by conflicts of interest.

### **Preventing Conflicts in the Future**

One of the roles recommended for ECs is that of education [1]. One of the most effective means for an EC to function is to try to prevent the escalation of disagreements [2] through ongoing training for staff in dealing with conflict. Beyond teaching clinicians the skills to [deal with conflict](#), it is important to teach ethics committee members to recognize their own emotional reactions and to look for help dealing with high-stakes situations.

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## THE CODE SAYS

### The AMA *Code of Medical Ethics*' Opinions on Ethics Committees and Consultations

Danielle Chaet, MSB

The *Code of Medical Ethics* has two opinions specifically devoted to ethics committees and consultations. These are both important, as numerous opinions in the *Code* address processes of requesting ethics consultations for ethically complex clinical cases.

Opinions 9.115, "Ethics Consultations" [1], and 9.11, "Ethics Committees in Health Care Institutions" [2], both focus on guidelines for the functioning of these resources. Opinion 9.115 states first that "all hospitals and other health care institutions should provide access to ethics consultation services." It explains that explicit structural and procedural standards should be developed and consistently followed, examines issues of consent in the context of consultations, and recommends that a consultation service have a workload that allows it to be functional. Opinion 9.11 outlines similar guidelines for ethics committees, explaining that their function is advisory in nature and confined exclusively to ethical matters, and that the size and availability of the committee should be consistent with the needs of the institution. Procedures followed by the ethics committee should comply with institutional and ethical policies on confidentiality, and any denominational health care institutions should publicize the fact that particular religious beliefs are to be taken into consideration in a committee's recommendations.

#### What Are They?

Opinion 9.115, "Ethics Consultations," explains that a consultation

may be called to clarify ethical issues without reference to a particular case, facilitate discussion of an ethical dilemma in a particular case, or resolve an ethical dispute. The consultation mechanism may be through an ethics committee, a subset of the committee, individual consultants, or consultation teams.

The 1992 Joint Commission on Accreditation of Healthcare Organizations (JCAHO) manual requires that health care organizations "have in place a mechanism for the consideration of ethical issues arising in the care of patients, and...provide education to caregivers and patients on ethical issues in health care" [3].

#### Why Are They Important?

Principle VIII of the *Code of Medical Ethics* states that "a physician shall, while caring for a patient, regard responsibility to the patient as paramount" [4]. Ethics consultations

might be requested, for example, when it's unclear or controversial which action would best execute this responsibility. Ethics consultations, even at their most informal, can be essential for upholding the best interests of the patient because they give a physician a "reflective space" [5] in which to discuss the ethical complexities of a clinical situation with other professionals who are either formally trained in ethics or who have significant clinical ethics experience. Such consultations should include appropriate stakeholders (patients and their families or decision makers, for example, are often invited to participate) and the viewpoints of those who can help clarify the nature and scope of relevant ethical and empirical questions and identify possible solutions.

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## MEDICAL EDUCATION

### Roles of Student Ethics Committees in Preparing Future Physicians

Carolyn Johnston, LL.M., MA, PhD

Medical students undoubtedly experience ethical dilemmas and concerns about appropriate professional behavior during their training [1], and as medical practitioners it seems they will be “encountering ethical uncertainties and even dilemmas in their daily practice with increasing frequency” [2]. However, there is evidence that medical students’ abilities to identify and manage ethical dilemmas decline as they progress through their undergraduate education [3, 4]. The role of medical educators is to adequately prepare future physicians with the knowledge and skills to identify and address such challenges. Giving medical students opportunities to discuss ethical issues they encounter in practice can engage interest and promote relevant learning.

As adviser in medical law and ethics at GKT School of Medical Education, King’s College, London, I wanted a mechanism to engage students in the discussion of clinical ethics dilemmas to ensure that their teaching was translated into practice. I had previously worked as project officer for the UK Clinical Ethics Network, which supports clinical ethics committees in National Health Service (NHS) hospital trusts [5]. I am also a member of three clinical ethics committees in NHS foundation trusts in London, and I thought a student clinical ethics committee would be an appropriate format to enable informed and meaningful discussion of clinical scenarios raising ethical concerns for students. Medical students receive core teaching in ethics and law, and, following discussion of different formats with them, we decided that a meeting that students could attend if they wished and in which they could fully participate would provide a relaxed and informal format for case discussion. I set up the Student Clinical Ethics Committee (SCEC) at King’s in 2010 with a group of medical students. The general secretary of the European Association of Centres of Medical Ethics, Rouven Porz, considered at the time that it was perhaps “the first students’ ethics committee in Europe (in the world?)” (personal communication, 2011). The aim of the SCEC is to provide opportunities for students to consider the ethical and legal issues arising in a real case observed by a health care student in clinical practice and to think through the implications for clinical decision making. There is evidence that students enjoy case-based learning, and this method seems to foster learning in small groups [6]. The SCEC clearly has no remit for providing advice but is rather an educational tool and enables interdisciplinary discussion.

### **SCEC Meetings**

The original group of students who helped set up the SCEC considered what documentation would be necessary and decided to draft terms of reference. The terms of reference set out the objectives and processes of the SCEC, including format and frequency of meetings, who may act as chair, and how cases are referred for discussion. Additionally we drafted a framework for discussion, which is used to ensure that key issues are addressed in the discussion, such as patient capacity and preferences, views of those involved in the decision, and possible options and their outcomes.

Any medical or health care student may refer a suitably anonymized clinical case for discussion with the agreement of the overseeing clinician. The student (referrer) contacts me with an outline of the case (anonymized as much as possible) and identifies the questions he or she would like the SCEC to discuss. This information, with some suggestions for background reading (the referral form), is circulated to those attending the meeting.

Meetings are open to all medical and law students, nurses taking the postgraduate diploma, and master's degree students in medical ethics and are advertised through the University weekly news bulletins and emails to those who have attended before. They are held every month in the academic year at a regular time and venue and last 75 minutes. Numbers are limited to 20 per meeting; places are allocated on a "first come, first served" basis, with a waiting list.

The meetings start with brief introductions—name, course, and year of study of those attending—and the chair then invites the referrer to sketch out background information for the case to be discussed and the ethical issues to be addressed. The chair then opens the floor for questions to clarify factual issues, such as diagnosis, prognosis, decision making capacity, and other items of clinical or ethical relevance. All who attend are then encouraged to state and discuss their views. A number of students attend every monthly meeting, which has resulted in the development of camaraderie and trust in discussing and reflecting on sensitive and challenging issues.

Certificates of attendance are provided to those who have attended a minimum of two meetings in one academic year. The Institute of Medical Ethics awarded a grant to fund travel costs for medical students from other institutions to attend our meetings, and the SCEC format is now being replicated in other medical schools.

### **Learning from the SCEC Discussions**

The SCEC has discussed a wide range of cases over the years that illustrate the diversity and complexity of ethical issues arising in clinical practice. These include whether an elderly, frail patient who refuses treatment and wishes to die should be given electroconvulsive therapy; the role of a medical student who suspects domestic abuse in

the antenatal setting; and whether it is appropriate to insert a percutaneous endoscopic gastrostomy for an elderly man who has already pulled out a nasogastric tube. The SCEC meeting does not aim to “resolve” the case referred, but rather to enable an informed discussion of competing ethical issues, which might include respect for patient autonomy, harms and benefits of different treatment options or refusal of treatment, disclosing information to avert harm to others, and the role of compassion.

For example, a case discussion that focused on a request by a family that the grandmother, who does not speak English, not be informed of her terminal diagnosis prompted students to wonder about the role of cultural norms and about how, as future physicians, they could act with honesty and integrity when there is disagreement about what constitutes a patient’s best interests and how they would approach communication with and care of a family in distress. The journal *Clinical Ethics* has published a number of case discussions of the SCEC, co-authored by the student who has referred the case [7-10].

Not only do students draw on what they learn about ethics and law in the curriculum but they also develop and refine interpersonal skills, such as the ability to consider other options and differing views, to communicate and actively listen, and to facilitate discussion. Those who attend meetings of the SCEC have valued the depth of the discussion and the learning that follows from it. Feedback from those who have attended meetings is overwhelmingly positive:

“Thanks for organising the sessions throughout the year—it has certainly been an interesting and thoughtful experience.”

“It was a pleasure for me to be able to attend the SCEC meetings and I learnt a lot.”

“All health care students should have to attend one.”

“The meetings enhanced my ability to identify and effectively analyse complex ethical dilemmas.”

Students who attend have also reported feeling well supported and encouraged through the discussion of complex and challenging cases. Some of the students who have attended SCEC meetings go on to membership in NHS trust-based CECs upon graduation from medical school, highlighting that SCEC participation nurtures interest and provides early career training in clinical ethics [11].

## Development and Embedding in the Curriculum

Ideally, the SCEC format could be expanded as an educational tool to enable students to engage in ethical discussion in the later years of their medical training by drawing upon knowledge previously covered in the earlier part of the curriculum. Students could refer cases for discussion arising from their own experiences in particular specialities. We are now considering embedding a similar format in the curriculum for the final two years of the medical degree. This raises challenges about how to enable small-group discussion for a large group (King's has about 450 students per class year) and how to evaluate learning that flows from the discussion.

Setting up and running an SCEC can be time intensive, and administrative assistance is helpful to book rooms, manage numbers attending, and circulate documentation. It is essential to have the support of faculty and committed students in setting up such a form of clinical ethics training. The students who attend meetings have enthusiastically engaged in interesting and wide-ranging discussions, and learning has been disseminated through publication of some of the cases. This form of clinical ethics support provides relevant learning for current students and prepares them for the reality of clinical practice. There is no doubt that a form of clinical ethics support is of value to health care students as they develop their moral compass throughout their training.

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## IN THE LITERATURE

### Ethics for Ethicists? The Professionalization of Clinical Ethics Consultation

Rachel Yarmolinsky, MS

**American Society for Bioethics and the Humanities. Code of Ethics and Professional Responsibilities for Health Care Ethics Consultants.**

**<http://asbh.org/uploads/publications/ASBH%20Code%20of%20Ethics.pdf>. Published 2014. Accessed March 22, 2016.**

*No one ever said that codes are easy to write.*

*Thomas Beauchamp [1]*

Professionalism and codes of ethics are intrinsically tied. As professions establish themselves, their members write codes of ethics to help define the professions and who can be considered a professional. The codes explain why and how professions are deserving of trust, establish standards with specific guidelines for ethical practice, and designate who will have the authority to enforce standards [2].

One initial task for a code of ethics is to define the profession and exclude rivals. The 1847 American Medical Association (AMA) *Code of Ethics* [3] was part of a strategy to separate physicians from charlatans by excluding the latter from the society of scientifically trained physicians seeking standing and respect for their professional knowledge and expertise. Exclusion means setting standards, and setting standards requires specialized education requirements for professional membership, certification by standardized tests, methods of licensure and credentialing for practitioners, and accreditation for institutions that educate and employ them [2]. All of this is designed to create a sense of trust in the profession and the persons who practice it—a foundation for physicians' fiduciary relationships with members of the public.

Do clinical ethicists need a code of ethics? Since their expertise is in *ethics*, one might imagine they are aware of the ethical responsibilities of being a clinical ethicist and even that they are inclined to act virtuously [4]. Are they *ethics professionals* in particular? Many clinical ethicists are [already members of other professions](#)—bioethicists generally receive terminal degrees in a profession outside of bioethics, commonly in law, the health professions, philosophy, or humanities and owe allegiance to one or another code for members of professional societies, such as the American Nurses Association [5], the National Association of Social Workers [6], the Association of American Chaplains [7], the American Association of University Professors [8], the American Bar Association [9],

or the AMA [10]. Clinical ethicists may have academic degrees in philosophy or religion or another area of humanities or have a certificate or master's degree in bioethics; still others have clinical expertise in social work or chaplaincy. Given this range of expertise, formulating an ethics code for bioethics—which would, among other things, define exclusionary standards that extend or withhold professional membership—leads to an interesting and important question: if putting a clinician, a lawyer, and an academician in the same room to discuss bioethical issues adds invaluable richness and complexity to that debate, how can the field of bioethics maintain that multidisciplinary richness while carving out a distinct professional niche? While professionalization of the field may necessarily incur some loss in interdisciplinary exchange, keeping this question in the forefront may help in the realization of creative solutions to keep this interchange a vital element in the profession.

For decades, the multidisciplinary members of the American Association for Bioethics and the Humanities (ASBH) have debated these and related questions, shedding a good deal of both light and heat on the matter [11-37]. Although the first edition of ASBH's *Core Competencies for Healthcare Ethics Consultation*, published in 1998, came out *against* professionalizing the field of bioethics, due largely to the interdisciplinary nature of the field, it included a list of the special ethical obligations of clinical ethics consultants [38]. In a widely discussed 2005 article, Robert Baker argued that the time had come for bioethics "to assert its integrity and independence" as a professional field by drafting a code of ethics [39]. That same year, ASBH formed a committee to draft a code of ethics for bioethicists; in 2009, another committee was formed to draft a code narrowly focused on health care ethics consultation (HCEC). By 2011, the second edition of the *Core Competencies* had reversed its previous direction; it now endorsed the establishment of professional standards for clinical ethics consultants and provided consultants with a discussion entitled "The Ethical Dimensions of HCEC as an Emerging Professional Practice" [40]. In 2014, ASBH published its "Code of Ethics and Professional Responsibilities for Healthcare Ethics Consultants" [41]. The move to professionalize bioethics is no longer in question, but the myriad [specifications](#) of that professionalism have just begun, as spelled out in this initial code.

A compelling and comprehensive overview of the history, development process, structure, and content of the code is provided by Anita Tarzian et al. in "A Code of Ethics for Health Care Ethics Consultants: Journey to the Present and Implications for the Field" [42]. Noting the controversies over the professionalization of ethics consulting, the need for a transparent and inclusive process of code formation, the diversity of professional ethics consultant duties, and the current lack of educational and professional standards or accountability in the field, the authors present a succinct account of the complex development process that produced the content of the code.

The code thus produced is addressed to bioethicists who practice clinical ethics consultation as well as to students and members of clinical ethics committees. Clinical ethics consultations take place in health care institutions, and, as noted in both editions of the *Core Competencies* [38, 40], the ethical responsibilities of and potential abuses to these institutions as well as to the patients and families they serve call for an ethical code specifically for clinical ethicists. While the preamble of the code [40] discusses the overall duties of the clinical ethics consultant and the specifications included in the code's seven elements address these specific needs, as outlined below, it is not far-fetched to imagine these elements applying to the entire field of bioethics, with different specifications laid out for the different roles and duties encountered across the field. Indeed, these elements closely overlap with those in one of the precursor documents to the ASBH code, the (as not yet adopted) "Model Code of Ethics for Bioethics" under development by the Canadian Bioethics Society, which is addressed to the entire field of bioethics [43].

### **The ASBH Code**

In an introduction provided for teaching purposes, ASBH notes that the code is a tool for students to learn about the responsibilities involved in ethics consultation and for consultants to use for self-assessment. It "does not discuss or endorse other aspects of professionalization, codify the knowledge and skill that consultants should possess, address *how* the code is enforced, [or] discuss evaluation criteria" [44]. These are serious limitations; without further specification and authority, the code could lose relevance over time if its aspirations remain symbolic and do not materially support the integrity of the profession and its fiduciary responsibilities.

The ASBH Task Force for Quality Attestation is currently piloting a program to certify individual clinical ethics consultants [45]. Once operational, this program will provide standards for evaluating the competence of consultants. Assuming that appropriate training requirements and penalties for unprofessional behavior will then be included in the code, the pilot program will eventually provide a basis for enforceable standards for the first "statement," or principle, in the code: "Be Competent" [40].

The second statement, "Preserve Integrity" [40], counsels consultants to be worthy of trust by acting in a manner consistent with both personal and professional core beliefs and values and recusing themselves when there is a conflict. The third, "Manage Conflicts of Interest and Obligation" [40], identifies conflicts and suggests strategies of avoidance, recusal, and disclosure to manage them. The role of the hospital or health care organization in this area is the elephant in the room; to help enforce this statement, ASBH should find ways to influence hospital policies to acknowledge and address conflicts of obligation in ethics consultation—such as when an ICU director has pressure to limit length of stay for a patient whose interests are better served by a longer admission. The preparation of ASBH guidelines on writing hospital policy for ethics

consultations, intended for hospital administrators, might help the individual consultant reconcile conflicts between staff duties and ethics consult duties. Guidelines for managing entrenched power structures in health care settings would also be helpful.

The fourth statement, "Respect Privacy and Maintain Confidentiality" [40], reiterates established Health Insurance Portability and Accountability Act (HIPAA) rules in the context of ethics consultations and helpfully discusses legitimate uses of information and how to manage confidentiality. The fifth and sixth statements relate to consultants' obligations to the field of bioethics. "Contribute to the Field" and "Communicate Responsibly" [40] ask consultants to advance the profession by conducting research, publishing, teaching, mentoring, and participating in professional organizations, on the one hand, and, on the other, to limit themselves to speaking about their area of expertise and to keep in mind the lay reactions to sound bites on controversial issues when communicating in public venues. These last two elements in particular could easily apply to any bioethicist serving within or outside health care institutions, across the spectrum of bioethicists' responsibilities.

The last statement in the code, "Promote Just Health Care within HCEC" [40], is profoundly aspirational. Its presence asserts that justice is an essential consideration in the context of ethics consultation. The code notes that clinical ethicists need to be attentive to disparities, discrimination, and inequities in health care contexts, and urges clinical ethicists to identify and include voices of marginalized patients, clinicians, or other stakeholders. They must ensure that access to and processes of ethics consultation are fair and not biased by issues of power, privilege, and organizational culture. As ASBH explains, "recommendations of the consultation should not reinforce injustice. When possible, consultants should identify systemic issues constraining fair outcomes in HCEC and bring these issues to the attention of individuals or groups in a position to address them" [46]. Of all the ethical issues addressed in the code, preventing or righting injustice may be the most difficult to realize.

### **Conclusion**

The influence of a code of ethics lies in its usefulness and relevance. Ideally it is a living document that is regularly updated to reflect changes in the field. ASBH and its committee members have formulated a code of ethics that represents the first efforts of the bioethics community to come together, to agree on values and responsibilities, and to move forward the untidy process of professionalizing bioethics consultation. An unanswered question is whether ASBH is continuing work on a code of ethics for bioethics as a profession. If so, will the current code for clinical ethicists be incorporated as a subsection or enlarged and adapted for different areas of bioethicists' professional responsibilities, which can include scholarship, research, teaching, and interacting with the media? What are barriers to a comprehensive code for bioethicists across settings

and roles? Whether and how the code will prove useful, grow, and flourish will depend on ASBH members' and committees' continuing efforts.

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## STATE OF THE ART AND SCIENCE

### Health Care Ethics Consultation via Telemedicine: Linking Expert Clinical Ethicists and Local Consultants

Alexander A. Kon, MD, and Maj. Robert J. Walter, MD, DHCE

#### Narrative: A Family Meeting

Dr. and Mrs. Jones are an elderly couple living in the same house where they raised their five children. For the past decade, Mrs. Jones has been increasingly confused, and she now requires in-home assistance most of the time. Recently, Dr. Jones has become more confused as well. Dr. Smith is the primary physician for both Dr. and Mrs. Jones, and, at a recent appointment, the couple's oldest son, Tim, reported that on several occasions in the past month Dr. Jones became violent towards his wife. Tim asked Dr. Smith to prescribe sedatives for Dr. Jones—not enough to make him sleep, but enough so that he would become less agitated and not lash out at his wife. Dr. Smith considered the request but was uncertain whether prescribing a medication to Dr. Jones for the benefit of Mrs. Jones would be appropriate. Unsure how to proceed, Dr. Smith contacted the on-call ethics consultant at his hospital for assistance.

Nurse Williams was carrying the ethics pager. When she received the call, she discussed the case with Dr. Smith and met with Tim to get further information. Although Nurse Williams was assigned to carry the ethics pager and had attended a one-week "bioethics intensive" course at Johns Hopkins University, she was not sufficiently trained to address such a complex case alone. Accordingly, Nurse Williams contacted the clinical ethicist, Dr. Brown, at a university hospital approximately 100 miles away.

Dr. Brown discussed the case with Nurse Williams and then called Dr. Smith for more information. Based on these discussions, Dr. Brown formed a preliminary recommendation; however, understanding the complexity of the case, he requested a meeting to include Dr. and Mrs. Jones's five adult children, Mrs. Jones's in-home assistant, and Dr. Smith. Nurse Williams scheduled the conference in the hospital's telemedicine suite so that Dr. Brown could participate via videoconference. Prior to the meeting, Dr. Brown and Nurse Williams discussed how best to structure the discussion.

Nurse Williams started the meeting by having everyone introduce themselves. She then asked Tim to discuss his concerns and his ideas for potential solutions. As Tim was talking, Dr. Brown saw an uneasy look come over the face of Sally, one of the couple's daughters. After Tim finished talking, Mrs. Jones's assistant affirmed that on several occasions Dr. Jones had been violent towards Mrs. Jones. As the group talked, it seemed

that there was a growing agreement that providing a mild sedative to Dr. Jones might be appropriate. Dr. Brown noted that Sally was looking down throughout this discussion and seemed to be fidgeting. Dr. Brown then addressed Sally directly, asking her opinion. At this prompt, Sally explained that though her father was a physician, he had always been opposed to medications. He refused to give his children aspirin, antibiotics, or any other medications, and he himself refused to take any medications even after developing high blood pressure. She expressed her belief that her father would never take a sedative.

Dr. Brown asked the other children, and they all agreed. Tim said that if Dr. Smith prescribed the medication, they could slip it into his father's food without him noticing. At this point, the children began arguing. The tension between the siblings increased, and Nurse Williams stepped between two of the siblings to de-escalate the argument. Nurse Williams was thereby able to calm the participants and lead the group back to the discussion.

During the course of the discussion, Dr. Brown and Nurse Williams probed deeper into the risk that Dr. Jones posed to Mrs. Jones. They noted that, if Dr. Jones was indeed violent towards his wife, it would be imperative to contact adult protective services and potentially separate the couple. The children and Mrs. Jones's assistant stated that these incidents occurred when Mrs. Jones needed help in the bathroom. When she called for help, Dr. Jones would come to assist, and Mrs. Jones often scratched or hit him due to her dementia. Due to Dr. Jones's confusion, at times he responded to these "attacks" by slapping her. The children and assistant do not believe that these occurrences place Mrs. Jones at risk, and all agree that there is no need for emergent intervention; however, all agree that finding a solution to this problem is essential.

At the end of the meeting, Nurse Williams thanked everyone for coming and thanked Dr. Brown for participating. She and Dr. Brown spoke about recommendations. Based on the conversation, they gathered that medicating Dr. Jones would be contrary to his longstanding beliefs and practices and would feel deceitful for his children and caregivers. As such, Dr. Brown advised that such a course of action would not be ethically permissible. He and Nurse Williams discussed other potential solutions (e.g., increased in-home assistance, relocating the couple to an assisted living facility, separating the couple, contacting adult protective services), and Nurse Williams drafted a note addressing the history, ethics background, ethical analysis, and recommendations. She sent the draft to Dr. Brown (via Health Insurance Portability and Accountability Act [HIPAA]-compliant email), who made several recommendations for editing the note and sent it back. Nurse Williams then finalized the note, placed a copy in the patient's chart, and discussed the recommendations with Dr. Smith.

## **Remote HCEC**

Competency in health care ethics consultation (HCEC) requires significant training and experience. Although the American Society for Bioethics and Humanities (ASBH) has published core competencies necessary for those who provide HCEC [1], most organizations continue to rely on untrained or minimally trained volunteers (such as those who have attended a one-week intensive course) for such services. A survey of 40 Maryland hospitals with ethics committees found that only 11.4 percent required any training or apprenticeship for personnel performing HCEC [2], and two surveys found that less than half of people who perform HCEC had formal training in clinical ethics [2, 3]. As such, it is not surprising that many clinicians believe that their ethics consultants are unqualified and, therefore, do not request consultations [4]. In response to the lack of local HCEC expertise, some organizations now contract with larger hospitals or universities to provide support for HCEC, which has paved the way for remote HCEC.

## **Modes of Remote Health Care Ethics Consultation**

In our experience, remote support for HCEC can be provided in several ways: email, telephone, or telemedicine (two-way audiovisual conferencing, often augmented by electronic access to medical records including laboratory and radiological studies) [5]. Several vendors sell prepackaged telemedicine systems (e.g., GlobalMed, AMD Global Telemedicine, Rubbermaid Healthcare), and experts have published recommendations for centers that wish to develop such programs [6]. When developing any telemedicine program, however, centers must be cognizant of measures necessary to protect private health care information (PHI), and, in the United States, such systems must be compliant with HIPAA [7].

In considering each of the above modalities for providing remote HCEC support, it is necessary to reflect on the overall goals of the HCEC process. According to ASBH:

The general goal of HCEC is to improve the quality of health care through the identification, analysis, and resolution of ethical questions or concerns. This general goal is more likely to be achieved if consultation accomplishes the intermediary goals of helping to: (1) identify and analyze the nature of the value uncertainty or conflict that underlies the consultation; and (2) facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights and responsibilities of all those involved. Successful HCEC will also serve the goals of helping to promote practices consistent with ethical norms and standards; informing institutional efforts at policy development, quality improvement, and appropriate utilization of resources by identifying the causes of ethical concerns; and assisting individuals and the institution in handling current and future ethical problems by providing education in health care ethics [8].

Each modality for providing remote HCEC support has strengths and weaknesses with respect to these goals, and we (both authors) have employed each at various times depending on the situation, resources available, and needs of those requesting assistance with complex HCEC.

*Email.* Email is often extremely helpful because it enables those requesting a consultation to do so at any time on any day and the expert consultants to respond when they are able. Although this method of communication might be the most flexible, in our experience it can be difficult for those requesting consultations to explain the nuances of an ethically and clinically complex case in an email, and it can also be challenging for the requester and expert to have an effective dialogue about the case. Further, PHI can only be sent over an encrypted, secure system but, because some requesters might not use that type of email, it can be impossible to provide sufficient detail. As such, we find that email alone is generally a suboptimal system for such support in most cases.

*Telephone.* Telephone is perhaps the most common form of communication for remote consultation assistance. With the ubiquity of cell phones, requesters can immediately access experts. Furthermore, because it doesn't require the same kind of encryption technology as email, telephone communication allows more detailed discussion of clinically and ethically complex issues and nuances of a case regardless of an individual's technological resources. Such communication may be augmented with HIPAA-compliant email, which facilitates the transmission of background case materials to and from the expert and also allows the expert to send a note that can be placed in the patient's chart.

A significant limitation of telephone communication, however, is the inability of the expert to "be present" in a family meeting. As noted in the case presented above, Dr. Brown's ability to observe affective cues was integral in revealing and exploring essential elements of the case. Therefore, although telephone communication can be an excellent way for requesters and experts to communicate one-on-one, the telephone is unhelpful when careful discernment of affective cues from participants is needed.

*Telemedicine.* Telemedicine provides many of the benefits of telephone consultation, but it also allows the expert to see all participants in discussions. In our experience, the ability to see who is talking and observe nonverbal cues of the speaker and others present can be essential in such cases. As noted in the case presented here and in cases we have presented previously [9], seeing participants' physical state (facial expressions or posture, for example) is often critical.

Although telemedicine has significant advantages, there are also significant [barriers](#) to using such technology. In our experience, telemedicine systems are expensive and require ongoing technical support and expertise. Local and remote telemedicine systems

must be compatible, and such communication must be HIPAA-compliant. Systems require high-speed connections, which can be difficult to guarantee in some remote locations. Furthermore, in many areas of the world, the necessary bandwidth can be impossible to procure without integrating satellite communication, which raises further privacy concerns.

### **Recommendation**

In our experience with facilitating family meetings (both in-person and remote), we would argue that the use of a remote expert cannot replace having someone physically present at the location. We therefore believe tele-HCEC should be considered as a tool to link a local consultant or meeting facilitator with a remote expert in clinical ethics.

Firstly, we believe it would be difficult for an expert clinical ethicist to effectively facilitate a family meeting via telemedicine. There are times when the meeting facilitator's physical presence is critical. As noted in the case presented here, the ability of Nurse Williams to physically insert herself between the siblings de-escalated the conflict. In family meetings, a facilitator might place a hand on a sibling's shoulder, give a patient's spouse a hug, help support a swooning parent, or otherwise provide physically demonstrable support to family members. These powerful gestures are impossible without physical presence. As such, we believe that, whenever possible, such meetings should be facilitated by someone who is physically present and that the expert should participate (but not facilitate) via telemedicine. However, when a remote location has no one sufficiently skilled and experienced to facilitate a family meeting, the only option may be to rely on an expert clinical ethicist to act as facilitator via telemedicine.

Secondly, HCEC involves reviewing medical records; talking with clinicians, nurses, and other staff members; seeing patients and talking with them as well as with family members; and organizing and scheduling meetings with staff or with family members. Such tasks can be more easily executed when someone is on-site to gather significant data prior to, or in tandem with, expert assistance. Prior to a consultation via telemedicine, a local consultant should provide significant background material to the expert [9].

Furthermore, ethics consultants doing remote consultations must be cognizant of legal and ethical issues that can vary by location and culture. For example, because laws regarding the unilateral withdrawal of life-prolonging interventions over the objection of the surrogate decision maker vary by state and country, an expert clinical ethicist must be well versed in the relevant norms and laws when providing support to clinicians in another state or country. Similarly, if a clinical ethicist were to provide HCEC support for a case in another country, local norms and laws could be significantly different than the norms and laws that the expert usually relies upon. Because HCEC relies heavily on cultural norms, statutes, and case law, a clear understanding of the relevant customs

and laws is essential. For example, all states in the US recognize death by neurological criteria, but many other countries and cultures do not accept such patients as dead; therefore, if an American clinical ethicist were to assist with a case in such a country, the consultant would need a good understanding of the local laws and customs regarding patients in permanent coma. As such, whenever expert clinical ethicists provide support to a remote location, knowledge and understanding of local norms and laws is essential.

### Conclusion

HCEC via telemedicine offers a unique opportunity to enhance access to qualified clinical ethicists, provide support for medical professionals, and improve care for patients and family members. There is growing interest in the professionalization of HCEC, and ASBH is moving toward development of a national certification process for trained and qualified HCEC consultants [10]. As tele-HCEC support is increasingly deployed, it will be essential to perform well-designed research to help clarify how such services can be enhanced to meet the needs of health care professionals and the patients and families they serve.

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## STATE OF THE ART AND SCIENCE

### International Access to Clinical Ethics Consultation via Telemedicine

Katrina A. Bramstedt, PhD, MA

#### Introduction

Clinical ethics consultation (CEC) is a service provided by clinical ethicists (or sometimes, clinical ethics committees) to enhance patient care by identifying, analyzing, and resolving ethics dilemmas in clinical settings [1]. CEC has long been offered as part of health care services in the US [2, 3], but it is less common in other countries, perhaps because of a lack of trained personnel due to limitations in the number of clinical ethics fellowships [4-6]. A result of this relative lack of clinical ethics training is that, in some parts of the world, CEC is either not available or it is performed by unskilled personnel [3].

Collegiality and the duty of care are two important and linked ethical values in health care. Clinicians should call on the help of colleagues when cases are complex, and this includes seeking the help of clinical ethicists as needed [7]. An ethical duty of care requires that health care workers be skilled in their professions [8]; thus, sending unskilled ethicists to perform CEC is problematic. According to the American Medical Association, "A [clinical ethics] consultation service should be careful not to take on more than it can handle" [9]. This suggests that practicing outside the scope of one's skill set should be avoided in favor of seeking skilled ethicist colleagues [9]. Everywhere ethical dilemmas arise in medicine, competent ethics consultation should be used.

Clinical ethics dilemmas are not limited to large academic medical centers, where clinical ethicists typically reside. Community hospitals face ethical dilemmas [10], as do rural hospitals [11]. Additionally, clinical ethics dilemmas occur in a wide variety of specialties, including neurology [12], organ donation and transplantation [13], pediatrics [14], and intensive care medicine [15]. Some of these dilemmas need urgent resolution [16], and thus timely access to skilled CEC is valuable.

Interactive telemedicine for remote, real-time communication that uses telephone, email, and videoconferencing technologies [17] might also be a way to provide CEC directly to patients as well as organizations (e.g., hospital departments and committees), in the same country or in other countries. As I discuss below, low-cost tools are available that make remote consultation feasible.

Telephonic CEC is valuable in the setting of transplant ethics consults, particularly for the [screening of living organ donor candidates](#). Many potential living donors do not live near the organ transplant center [18] (e.g., out of state, out of country), and telephonic screenings can reduce costs (e.g., travel, accommodation, food) for the donor candidate and add efficiency to the screening process. While these candidates might be clinically suitable in terms of blood type compatibility, and while they might have undergone a telephonic screening by the social worker beforehand, the clinical ethics consultant can screen for ethical and psychosocial measures of suitability telephonically. Based on my experience, examples of exclusions assessed during telemedicine CEC screening are lack of motivation or ambivalence about donating, coercion, lack of an altruistic motive for donation, moral distress about donating, inability to provide informed consent for donation, and conflict of interest (e.g., desire for compensation or personal gain or a large power differential between potential donor and recipient, such as an employee-employer relationship). After the CEC, the ethicist can make additional referrals to other specialists as needed, such as psychiatry or pastoral care.

### **The Australian CEC Telemedicine Experience**

Australia is known for its large size and unusual dispersion of population; specifically, the geographic distribution is such that most residents live in the coastal perimeter (due to moderate temperatures), with far fewer residents living inland or in rural areas [19]. The first use of telemedicine in Australia was reported in 1929, when the pedal radio was used by the Royal Flying Doctor Service in Queensland to allow doctors to communicate with nurses about patient care in the outback [20]. Possibly due to telemedicine now being widely available, less than 3 percent of the Australian population travels more than one hour to see a general practitioner [21].

With the arrival of a fellowship-trained clinical ethicist, Bond University's medical school initiated a CEC service (in-person and remote) in 2012. Because of its direct link to several local teaching hospitals, the CEC service was poised to offer both inpatient and outpatient consults. And because of the ethicist's specialty in transplant ethics, the service provides this specialty consultation nationwide as well as internationally using telemedicine technology (phone, email, videoconferencing) [22].

Since January 2013, a CEC registry has formally recorded consultations [23]. As of December 2015, this CEC service had performed 46 telemedicine consults, mostly on the topic of transplant and donation ethics (91.3 percent). Most telemedicine consults (82.6 percent) were performed for international clients in various countries, including the USA, Canada, and Switzerland. Technology use for international clients was as follows: 52.6 percent (20 of 38) of consults were by email, 42.1 percent (16 of 38) by telephone, and 5.3 percent (2 of 38) by videoconferencing. Direct patient contact/interview was involved in 57.9 percent (22 of 38) of international telemedicine CECs. All patients who were directly contacted/interviewed were outpatients and all were offered the opportunity of

videoconferencing via Skype or FaceTime, but 72.7 percent opted for telephone consultation (because of, e.g., lack of access to these technologies and concerns about data usage for a 45-60 minute consultation), the cost of which is borne by the caller (clinical ethicist). Telephonic interpreters have been used for Spanish- and Arabic-speaking patients. Consults not involving direct patient contact were focused on matters pertaining to research ethics, organizational ethics, or a deceased patient.

### Lessons Learned

Planning for and structuring of international CEC are required to ensure safety and efficacy (see table 1).

**Table 1.** Avoiding logistical problems in telemedicine clinical ethics consultation

Potential problem	Solution tool
Multiple time zones	Electronic world clock meeting planner
Language barrier	Translator arranged prior to consultation
Lack of costly formal videoconference system	Skype, Skype for Business, FaceTime
Need for access to medical records for review and to create consultation notes	Remote chart access or copy transmitted via encrypted email

*Time zone differences.* When international CEC is performed, both participating locations must be aware of the time zone difference, especially when the International Date Line is crossed. For example, a consult planned for 8:00 a.m. Friday in Brisbane will occur at 2:00 p.m. Thursday in Los Angeles—but only during Daylight Savings Time (which Los Angeles observes, but Brisbane does not). The use of an electronic world clock meeting planner [24] can be very helpful to ensure all parties show up at the same time.

*Language barrier.* Foreign languages can be a challenge in international CEC. Some hospitals have on-site translators, while others use phone interpreter services. Both are suitable for international CEC, but these services must be reserved in advance. It is helpful if the hospital or clinic arranges these translator services for the ethicist. Family members should not be used as translators due to the emotional challenges of ethics consultation, the risks of lack of objectivity, and their lack of experience with the health care context [25].

*Prohibitive cost of videoconferencing systems.* Videoconferencing systems can cost \$20,000-\$30,000 [26], an expensive price tag for many rural or small facilities. This high cost would also make it difficult for private practice ethicists and even bioethics centers to have their own systems [26]. A much simpler and more cost-effective video communication system is online videoconferencing software. Skype [27] is available in two formats: Skype (free) and Skype for Business (requires a monthly fee). Both formats allow users to communicate with each other via text, audio, and video, and both use

suitable encryption technology; however, only Skype for Business is compatible with the Health Insurance Portability and Accountability Act (HIPAA) [28, 29]. (In fact, Skype for Business is bundled with MDLIVE telemedicine and telepsychology services [30].) FaceTime, for Apple devices, is a free, HIPAA-compliant videoconferencing platform that is used by the United States Department of Veterans Affairs [30, 31].

Of course, in other countries compliance with HIPAA is not required. For example, the Australian College of Rural & Remote Medicine argues that the personal version of Skype is suitable for telemedicine use for nonurgent consults lasting less than one hour (to ensure call quality) and emergency consults, but not for texting patients or file sharing [32]. Telemedicine consults using the personal version of Skype are also permitted by the Australian Department of Health and Ageing and Australian Medicare (public health service) [32]. This policy is reasonable, as it might not be feasible for all patients, hospitals, and ethicists to have expensive videoconferencing systems or Skype for Business accounts.

*Need for access to medical documents.* The performance of telemedicine CEC requires review of the patient's medical record, and there are two ways of accomplishing this. The facilities that request the consultation can arrange for direct electronic access to health records through remote login procedures, although training might be required to navigate the electronic health system. Another option is for the requesting facility to send portable document format (.pdf) files through encrypted email. The facility can provide a secure email account that allows direct entry into their regulation-compliant system. These technologies can also be used for depositing the CEC report into the patient's medical record [33]. Private practice clinical ethicists can also use free, HIPAA-compliant email servers for communication with patients and organizations [34].

## **Conclusion**

Telemedicine allows the remote presence of trained and experienced clinical ethicists directly in inpatient and outpatient settings across the world. Interpreters can bridge the gap in settings of foreign language, and low-cost telemedicine technology can be used in resource-poor areas. No longer shall the availability of CEC be limited to academic medical centers.

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## POLICY FORUM

### Strategies to Improve Health Care Ethics Consultation: Bridging the Knowledge Gap

Ellen Fox, MD

Serious concerns have been raised about the quality of health care ethics consultation (HCEC) services in US hospitals, the fact that these services operate with little oversight, and the possibility that low-quality HCEC might harm patients [1-4]. The largest and most comprehensive study of HCEC to date was published in the *American Journal of Bioethics* in 2007 [1]. It found, among other things, that: significant resources are devoted to HCEC; HCEC practices vary widely; many HCEC practitioners have little training; and HCEC services are rarely evaluated for quality. This study was received as a “wake-up call” [3] by the bioethics field and catalyzed several national quality improvement efforts.

In the wake of this study, the American Society for Bioethics and Humanities (ASBH) spearheaded several projects designed to [improve HCEC quality](#). Most significantly, ASBH published a report on core competencies for HCEC that establishes specific quality standards [5]. ASBH has also developed an education guide for improving HCEC competencies [6]; a report on certification, accreditation, and credentialing [7]; a code of ethics for ethics consultants [8]; and a portfolio review process to assess the competency of HCEC practitioners [4]. Meanwhile, other groups have advocated for different strategies to improve HCEC quality. For example, one group proposed a written certification exam for HCEC practitioners [9, 10]. Other groups have proposed credentialing and privileging HCEC practitioners at the hospital level [3, 11, 12]. Still others have proposed accrediting HCEC services at the program level, as is done for institutional review boards [13, 14].

Right now, ASBH leadership is debating whether to pursue a certification process for HCEC practitioners, and the organization is [poised](#) to make critical decisions about next steps. The problem is that policy discussions are primarily taking place among members of the academic bioethics community who lack critical information about the US hospitals they seek to change. The field of bioethics in the US, including its national organizations and published literature, is dominated by academics who work in or are closely affiliated with universities. Bioethicists who practice HCEC typically do so in large teaching hospitals with relatively high-volume HCEC services. Some of these hospitals have multiple paid bioethicists on staff and perform up to 300 consultations per year [1].

But such hospitals are far from [typical](#). The majority of US hospitals are quite small: a survey of 653 hospitals found that 74 percent have fewer than 200 beds, 54 percent have fewer than 100 beds, and 33 percent have fewer than 50 beds [15]. More than three-quarters of 6,317 US hospitals have no medical school affiliations or residency programs [15]. And the “typical” US hospital performs very few consultations; based on data from the 2007 study, an estimated 19 percent of US hospitals have no HCEC service, and, in the majority of hospitals that do, the service performs between zero and three consultations per year [1].

To maximize the impact of improvement strategies, policymakers should target “typical” US hospitals, instead of the small fraction of hospitals that already have a bioethicist. Making assumptions about US hospitals by extrapolating from bioethicists’ experiences could lead to poor policy decisions. For example, the ASBH core competencies report distinguishes between basic-level HCEC competencies (required to handle straightforward cases) and advanced-level competencies (required for more complex cases) [5]. Based on the experiences of bioethicists, policymakers might reasonably assume that most hospitals need people with advanced-level HCEC competencies, and, as a result, might focus their improvement efforts on certifying HCEC practitioners at the advanced level. But what if the hospitals with the greatest quality problems rarely if ever encounter cases that are complex enough to require advanced-level HCEC competencies? In that case, an improvement strategy focusing on advanced-level competencies would be ineffective in hospitals that need it most.

To make prudent decisions, policymakers need to better understand: (1) current HCEC practices in US hospitals, (2) the gap between current practices and the quality standards established by ASBH, and (3) the perspectives of key stakeholders, especially in “typical” US hospitals.

First, there is a need for up-to-date information about HCEC practices. Much has changed since 2000, when the prior national study was completed. More recent studies have examined HCEC practices in a single US institution [16–21], at institutions outside the US [22–26], and at 44 children’s hospitals [27]. But none of these studies can be used to draw conclusions about general hospitals in the US.

Second, there is a need to understand the degree to which HCEC practices are consistent with newly established ASBH quality standards. To develop appropriate strategies, policymakers need information about specific quality gaps. Understanding how HCEC quality relates to HCEC service characteristics (e.g., consultation volume, level of training) would help policymakers further target interventions to maximize impact [28]. Ideally, HCEC quality should be assessed not only through survey methods, but also through review of HCEC records.

Third, policymakers need to understand the perspectives of key stakeholders to determine which improvement strategies would be most effective. A recent study asked a convenience sample of people who subscribe to national bioethics listservs about their preferred methods for assessing and improving the competence of HCEC practitioners [29], but most respondents were ASBH members and 70 percent had received advanced training in medical ethics (27 percent at the doctoral level, 26 percent at the master's level, and 17 percent in a certificate program or fellowship). These respondents are not at all representative of US hospitals, in which, one sample indicated, only 5 percent of HCEC practitioners had completed a fellowship or graduate degree program in bioethics [1].

For improvement strategies to succeed on a national level, they will need to appeal not just to the academic bioethics community but also to key stakeholders in hospitals more generally—especially the thousands of HCEC practitioners and hospital administrators who are directly responsible for HCEC practices but may have little or no connection to ASBH or the national academic bioethics community. To change practices on a broad scale, policymakers will need to influence stakeholders in “typical” hospitals, and, to do this, they need to understand stakeholder perspectives and values.

To help fill this knowledge gap, my team from the Center for Ethics in Health Care at the Altarum Institute is embarking on a new research study, supported by a grant from the Greenwall Foundation. We will ask HCEC practitioners and administrators in a random sample of 600 US hospitals about their HCEC practices and their views on potential improvement strategies. We also plan to assess HCEC quality through a review of 300 written consultation records using a rigorous scoring method I developed with my former colleagues at the National Center for Ethics in Health Care [30].

The Altarum study will answer the following questions:

- How have HCEC services changed since 2000? For example, has the level of training received by HCEC practitioners increased or decreased? Has the volume of HCECs changed?
- How do HCEC practices compare with recently established ASBH standards? For example, are hospitals meeting ASBH standards for documenting HCECs? Are HCEC services being evaluated as ASBH recommends?
- What are the perspectives of HCEC practitioners? For example, do they believe that the resources devoted to HCEC are sufficient? What do they think about ASBH standards for HCEC? What strategies to improve HCEC do they think would be effective?
- How much do hospital administrators know about HCEC services, and do their perspectives differ from those of HCEC practitioners?

- What is the relationship between hospital characteristics, HCEC service characteristics, HCEC practices, perspectives of HCEC practitioners, and perspectives of hospital administrators?
- How do hospitals score on HCEC quality as determined by systematic review of written HCEC records, and how do these scores relate to the variables above?

We hope and expect that the answers to these questions will help policymakers develop effective strategies to improve HCEC quality, especially in those hospitals that are most in need of improvement.

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## MEDICINE AND SOCIETY

### Health Care Ethics Committees as Mediators of Social Values and the Culture of Medicine

Cynthia M.A. Geppert, MD, MA, MPH, MSB, DPS, and Wayne Shelton, PhD

Health care ethics committees (HCECs), bodies that mediate ethical disputes and dilemmas in patient care settings, began in the 1960s, assumed a prominent organizational role by the 1970s and 1980s, and emerged by the 1990s as the primary institutional mechanism for studying, educating about, and providing advice on value conflicts and dilemmas in medicine [1, 2]. The development of these HCECs was triggered by broad social, legal, political, and technological changes, especially questions at the beginning and end of life. Many HCECs took a leadership role in their institutions in upholding ethical principles and legal standards and, through this role, influenced the prevailing culture of medicine [3]. The primary trajectory of this cultural movement was away from a paternalistic, physician-driven culture toward a more patient-centered, autonomy-based one, which is now well established in American medicine [4]. HCECs' influence historically was exercised through the three primary functions of HCECs: (1) ethics education, (2) policy development, and (3) [ethics consultation](#).

In each of these functions, HCECs tended to mediate between the values prevalent in medical culture and those of society more broadly. For instance, in our experience, it's now common for bioethicists to question the primacy of the principle of autonomy, no matter how individual freedom is prized in American society. As a mediating force, HCECs are in a unique position, for example, to help balance self-determination with other neglected considerations, such as the obligations of health care practitioners to do good and avoid unnecessary harm to their patients, as well as to use resources prudently and justly.

This kind of mediation requires the critical distance and capacity to see many perspectives. But HCECs, which some have argued began as a countercultural force to resist medical paternalism and to help guide and reshape the new ethical and social values of medicine, have at times risked becoming tools to reinforce and defend the status quo in medical culture [5]. In this commentary, we examine potential challenges to HCECs: lack of expertise in policy formation [6], an underdeveloped ability to differentiate ethical questions from other organizational concerns, threats to impartiality and independence, and external mandates to establish HCECs without adequate institutional support. Failure to effectively manage these challenges could potentially

undermine the HCECs' ability to fulfill their function as mediators between value systems.

### **Lack of Expertise in Policy Formation**

Policy in many health care systems delineates the scope of ethics consultation and the subject matter of the ethics education HCECs provide; it also articulates the values and culture of the institution's leadership and mission. Because policy plays this pivotal role at the interface between medicine and society, lack of training and expertise in policy development and implementation can impede and derail the other key functions of HCECs and lead to failure to effectively and authentically communicate the mission of the institution to the community. Compared to the rich and growing literature on ethics consultation, the policy function of HCECs has received less scholarly attention, even though most ethics committees spend more time on policy development and policy has potential to influence medical culture at a systems level [7]. To develop sound policy, it is important to be able to assess the numerous forces within medical and social culture—legal, regulatory, economic, political, clinical, and institutional—that help shape medicine and influence HCECs. One related challenge is that many HCECs do not have the background and expertise in organizational policy development needed to craft policies that balance institutional claims and counterclaims and respect the core principles and standards of medicine in addition to well-established ethical and social values [6]. The current debates about resource allocation and physician-assisted death are examples of areas that will require advanced proficiency in policy formation.

### **Underdeveloped Ability to Differentiate Ethical Questions from Other Organizational Concerns**

HCECs receive many types of questions and concerns—clinical, political, [legal](#), organizational, regulatory, and human resource-based—that would be more appropriately addressed through other organizational mechanisms. HCECs must be able to differentiate among these types of concerns, focusing on the true values conflicts where their expertise resides and referring non-ethics questions to the proper resources [8]. If HCECs offer legal advice or medical recommendations, they risk conflicts of interest, diffusion of efforts, professional resentment, and a corresponding loss of credibility and influence [3]. HCECs' members must be trained to recognize when concerns are ethical in nature—that is, when they pertain to a genuinely value-laden conflict or dilemma—and to be able to differentiate these from conflicts borne of other organizational pressures, such as liability concerns or financial constraints. HCEC members can enhance their capacity for ethical discernment, like many other analytical skills, through structured education and mentored practice. It has taken time for the fields of clinical ethics and bioethics to be helpful to HCECs in this regard. Indeed, respondents to one survey identified a lack of scholarly background and education as the most serious obstacle to HCECs fulfilling their promise [9].

### **Threats to Impartiality and Independence**

One function of HCECs is to uphold established legal, professional, and ethical principles and standards. Thus, HCECs must above all strive to wield authority with careful, deliberate regard for those who have stakes in the outcomes within the institutional power structure [3].

*The need for diversity of membership.* For mediation to be effective and balanced, HCECs' membership needs to be representative of not only the health care community, but also patient populations—both those who serve and those who are served. Currently, the membership of some HCECs is too homogenous to achieve this needed balance. Fox's landmark 2007 survey found that 34 percent of ethics consultants were physicians and another 31 percent nurses [9]. Chaplains and social workers have invaluable and traditional roles to play on HCECs, as do newcomers, such as midlevel practitioners who provide much of the primary care and a host of allied health professionals. The perspective of administrators is crucial for policy development, but the presence of higher-level administrators can (perhaps unwittingly) stifle deliberations in ways that raise conflicts of interest [5]. The place of attorneys at the HCEC table has been a subject of debate, but attorneys are often invaluable as a source of health law expertise, so long as their input pertains to helping elucidate an ethical perspective in relation to the law [10]. It's been well established that community members and patient advocates are increasingly found on ethics committees but that some committees do not have a trained bioethicist [4]. A wide-ranging interdisciplinary membership is needed to reflect the diversity of the culture of medicine and the society to which it provides care.

*Relationship to health care institutional power structures.* Maintaining critical distance and the impartiality to mediate and clarify the pressing value conflicts in education, policy, and consultation are key to HCECs retaining their integrity. For example, in our experience, if the HCEC teaches trainees and staff that shared decision making should be the model for practitioner-patient relationships, and yet the ethics consultation service routinely resolves ethical conflicts between patients and the health care team in the team's favor, then its impartiality can and should legitimately be [questioned](#); certainly a reputation for bias or favoritism could result in the HCEC not being respected or utilized. Ideally, HCECs should be structured in a way that avoids inconsistencies in case-by-case reasoning and approach and communicates to stakeholders a cohesive ethical vision. The Department of Veterans Affairs' (VA's) Integrated Ethics (IE) Program has been a national leader in this respect; it has established a comprehensive and structured approach to ethical concerns in health care. IE represents a "radical departure" from traditional ethics committees. Instead of dividing HCEC activity into its traditional three functions—policy, education, and consultation—IE focuses on continuous improvement of ethics quality at three main levels: the level of organization and culture ("ethical leadership"), the level of systems and processes ("preventive ethics"), and the level of decisions and actions ("ethics consultation") [11].

The VA's inversion of the HCEC paradigm beginning at the top underscores the importance of leadership commitment to the success of HCECs. For HCECs to constructively mediate between society and medicine they must have a measure of independence from the leadership of the hospital and an ability to examine the surrounding culture of medicine with an open mind and an even hand [5]. This independence is difficult to achieve in institutions where leadership chooses HCEC members and where the HCEC is dependent upon that leadership for administrative support, funding for training, resources, and, most importantly, dedicated time to do good work [12].

Similarly, the HCEC should articulate and promote the mission of the institution while maintaining the ability to critically question the organization when actions or proposals contravene or compromise even more fundamental values, such as social justice and human dignity. Such conflicts are most poignant and difficult in hospitals where other powerful social forces such as fear of litigation, the profit motive, political pressure, or religious beliefs may limit the ability of the HCEC to adhere to well-accepted standards of ethics consultation, policy development, and education [13]. The extent to which institutional leadership takes the advice of the HCEC seriously is a strong commentary on the ethical health of that institution.

### **External Mandate Without Adequate Institutional Support**

One standard of acceptance of HCECs in American medical culture is evinced in the publication of the American Medical Association's 1984-85 report, "Guidelines for Ethics Committees in Health Care Institutions" [14]. Additionally, regulatory acceptance culminated in 1992, when the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) mandated that hospitals seeking its approval have in place a means for addressing ethical concerns [15]. The mandate is often represented as specifically requiring institutions to have HCECs in particular, rather than any mechanism of responding to ethical issues. Certainly, HCECs rapidly emerged as the predominant means of meeting this requirement. A review of survey findings shows the exponential expansion of HCECs: in 1983, 1 percent of surveyed hospitals had HCECs; four years later, over 60 percent had HCECs; and in 1999, nearly 93 percent of American hospitals with more than 400 beds and every federally funded health care institution had an HCEC [7, 16, 17].

These studies identify, as one of the greatest obstacles facing HCECs, the lack of institutional support such as dedicated staff time, space, and resources. Many HCECs are composed of volunteers who often have dual or multiple roles in the institution, which, especially in small hospitals and rural communities, may create overlapping roles with the potential for conflicts of interest [11].

For HCECs to secure a solid place in organizational structures, they must demonstrate the value HCEC mediation contributes to institutional success. The current preoccupation

of the culture of medicine with measurability, understood in quantitative performance measures, will require HCECs to be disciplined and creative in demonstrating to institutional leaders the value of the mediating activity HCECs perform. This demonstration must be more than is required for the formalities of JCAHO approval and eventually should be based on empirical data. One potential area that HCECs could develop is increasing patient and family access to the ethics committee, especially consultation services, as a way of improving patient satisfaction. HCECs will need moral courage and discernment to reconcile core ethical principles and professional standards of medical culture at its best with increasing pressures in society toward commercialization and utility.

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## MEDICINE AND SOCIETY

### Understanding and Utilizing the Convening Power of Ethics Consultation

Joseph J. Fins, MD

#### Narrative: A Case in Conflict

"It was as if by magic." So said a thankful psychiatrist to the chair of the hospital [ethics committee](#). She was grateful and, truth be told, relieved that her patient had finally been transferred from the psychiatry to the medicine service [1]. It had been a long haul, a proverbial turf battle in which the medicine service did not want to accept a patient with severe mental illness despite medical need.

The patient, a woman in her early 20s, had been admitted to the psychiatry service with a psychotic depression and suicidality complicated by an eating disorder. After electroconvulsive therapy for medication-resistant depression, her affective symptoms eased and her suicidality passed. She was no longer an immediate threat to herself, but her anorexia was worsening. Her psychiatrist did not view her anorexia as suicidality, but rather as a condition that had likely precipitated the major depression.

Despite the placement of a nasogastric tube, the patient had lost 10 percent of her total body weight, and the psychiatry service was getting increasingly anxious about her care. Even with backup from the general medical consultation service, the psychiatrists were at the edge of their comfort zone and wanted her transferred to medicine. Physicians on the medical service disagreed, noting that the patient was stable and that involvement of a medical consultant was sufficient to provide support for her general medical needs. Besides, as they repeatedly protested, the medicine service was no place for such a psychiatrically ill patient.

The psychiatrist pushed back, explaining, as earnestly as she could, that her patient's affective illness had improved and that her major issues now were *medical complications* of psychiatric illness. The psychiatry service would gladly take the patient back when her general medical needs were addressed. The psychiatrist tried her best to be persuasive, viewing the medical service's ostensibly rational resistance as a kind of institutional countertransference, to borrow a psychoanalytic concept to depict the expression of unarticulated emotional angst—in this case, of one clinical service about another. Despite her frustration, she went through all the available channels, working with the medical chief resident who controlled bed assignments, the department of medicine's program director, and nursing leadership. All these efforts were to no avail. Resistance to such transfers had been a perennial problem due to the jurisdictional status of

psychiatric inpatients transferred to the medical service. (In some states the legal rights of patients on a psychiatry service are different than those of patients on a medical service [2].)

Finally, desperate for any sort of help, the psychiatrist asked for an ethics consultation. She felt that what was happening was wrong, even discriminatory, and not in the patient's best interest. The ethics consultant reviewed the chart, met the patient and her family, spoke with the psychiatrist and nurses on the psychiatry service, and inquired about the current status of psychiatric "scatter beds" on the medicine service. (These are beds on the medical service that are designated as psychiatry beds and thus regulated under state laws governing mental health [2].) The clinical ethics consultant also spoke with the general medical consultant, who thought the patient should remain on psychiatry, although he worried about the burden it placed on that service. As the clinical ethics consultant listened, he suspected the medical consultant could be pivotal in resolving the case.

So he did what all good clinical ethicists do: he set up a meeting to gather information from all the people in the room to work towards a consensus. As was his practice, he started with a round of introductions to try to keep participants' contentions at bay. After this welcome, he asked the group to review the clinical history. From long experience, he knew that conflict often stemmed from incomplete knowledge or understanding of the facts, rather than from fundamental disagreements. So it was a priority for him to try to establish a common evidentiary base for understanding the case's clinical complexities before moving on to explore its ethical dimensions [3].

Before the meeting, the clinical ethicist wondered if there were additional data points that could convince the medical service of the patient's clear medical need for transfer, sidestepping the problematic "scatter bed" issue. Although he believed psychiatry's reservations to be ethically dispositive, he hoped to find a more objective rationale for transfer. That is, the ethics consultant was looking for an objective bit of evidence that would clarify what was appropriate care in this case. In his view, it is always better to decide something on the facts rather than having to appeal to an ethical principle, about which people involved in patient care are more likely to disagree. Too much of bioethics is about principles, not enough is about cultivating the clinical narrative.

The patient's case was presented. She had a normal cardiogram on admission and her recent lab results were normal. When the psychiatrist was asked about medical indications for transfer, her response did not seem to convince the medicine team that the patient needed to be transferred to medicine.

The ethics consultant sought the input of the nurses and house staff, who were not sitting at the conference table. Prompted by this invitation, one of the medical residents

asked if the patient had *recently* had an EKG. Although the patient wouldn't be at risk for atherosclerotic heart disease, he worried that her rapid weight loss might have predisposed her to QT segment prolongation, visible on her echocardiogram, which would suggest the patient's increased risk for malignant arrhythmias, an obviously clinically relevant detail.

The chief resident responded that this risk was unlikely, prompting the ethics consultant to ask the general medicine consultant's opinion. He seconded the resident's suggestion and the EKG was ordered. The cardiogram revealed QT segment prolongation. With this additional key piece of data, all agreed transfer was necessary. Where there had been disagreement, there was now consensus.

### **Analysis**

One could argue that a failure to obtain a second cardiogram was bad medical practice, and perhaps it was. But upon deeper reflection, the cause of this avoidable oversight becomes more complex: the dynamic became oppositional between the psychiatry and general medicine teams, and this circumstance obscured clear thinking and good practice, which easily could have resulted in consequential morbidity or mortality had the teams' conflict persisted. Indeed, after the question of whether to transfer the patient had been resolved, additional concerns might surface about, for example, metabolic complications of the refeeding syndrome following the placement of a nasogastric tube. This sequence of events suggests how one bad judgment can prompt others and lead to a cascade of error, as noted in the Institute of Medicine study, *To Err is Human: Building a Safer Health System* [4]. Such a cascade of error is ethically consequential because these bad judgments multiply and potentially affect patient well-being and safety, becoming maleficent.

Fortunately, this unhealthy, even iatrogenic, dynamic was interrupted by the *convening power* of the ethics committee, which provided a [forum](#) to bring people together and cultivate the facts that led to the prevention of a possible harm due to previously unappreciated medical risks to this patient. By mediating conflict, bringing stakeholders together, and giving those stakeholders opportunities to hear each other, the ethics consultant enabled the emergence of clinically and morally relevant facts that led to the revelation that avoiding harm was an ethically important goal. The airing of these issues allowed the physicians to reconsider their oppositional stance and focus in common on caring well for the patient. In this way, convening was a powerful antidote to the defense mechanisms that can distort what Rentmeester and George have described as "clinical moral perception," the "capacity to accurately discern what is at stake for patients ethically and clinically" [5].

*Convening power and clinical ethics.* Convening power can be thought of as the power to bring together an expertly curated or directed group of diverse stakeholders to address a

clinically and ethically complex problem [6]. This capability of an ethics consultant is increasingly central to diplomacy, business, organizational reform, and social change.

This convening power stems from the ethics committee's authority and duty to appoint consultants who will field and respond to consultation requests and convene the consultation itself. Ethics committees' importance within health care organizations can be a product of their regulatory roles under the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) accreditation standards and responsibilities related to applicable state law [7]. Clinical ethics consultants should have special expertise in small group facilitation and other skills. These elements, combined with the committee's interdisciplinary reach across a broad swath of hospital and community constituencies, create a neutral space in which stakeholders can address and resolve consequential questions [8, 9]. The diplomatic function of ethics consultants can—as the case suggests—be central to promoting deliberation about clinically and ethically complex cases within an institution. Success in this arena in turn adds to the convening power of a committee. This is enhanced as a committee develops a reputation for fairness and procedural legitimacy and a resource for addressing and resolving ethically complex cases.

*Ethics case consultation and effective convening.* Successful ethics consultation hinges upon effective convening, a capability that needs to be understood and cultivated in the hospital setting. This process happens at three points: when the consultant is able to bring people together as he or she collects the clinical facts; when a group gathers to discuss an individual case; and when the institutional ethics committee comes together to review cases in the aggregate, set policy, and educate staff. With this in mind, let us return to the case to highlight several key elements of effective convening.

Long before a group is assembled, it is essential to gather information in a neutral and broad fashion both from the medical record and from conversations with stakeholders, such as caregivers, patients, and patients' loved ones. This process of collecting information also builds relationships and lays the foundation for fuller discourse and eventual consensus. In this case, knowledge of the general medicine consultant's ambivalence led to questions about the utility of a second cardiogram. This questioning was a subtle but pivotal intervention that was central to the outcome of the case. Although this case began with the exercise of good consultative skills, it needed the input of the group, properly convened to gain additional voices, which turned out to be dispositive.

The result hinged on the presence of the medical resident, which highlights the need to assemble the right people. While making this judgment requires experience, local knowledge of one's institution, and awareness of potential questions raised by an individual case, certain general rules pertain. These include having an interdisciplinary

team, the diversity of which is reflective of the people who work and are cared for at one's institution, and the ability to add expertise as necessary. And, most importantly, to make the most of the group, the convener must make it possible for the assembled to participate by flattening usual power structures, engaging diverse perspectives, and appreciating the moral agency of all in attendance. Making deliberations inclusive is more than a democratic urge. It is also a pragmatic necessity: if the conversation is held by a broadly constituted group of diverse individuals, the resulting consensus, if achieved, will be stronger and more resilient when tested later.

Skeptics about the importance of convening power to ethics consultation might note that elements of ethics case consultation are similar to interdisciplinary team meetings. The difference is that ethics consultations bring together groups with conflicting cultures, goals, and objectives. This makes an ethics consultation and an ethics committee meeting more an exercise in diplomacy than routine care meetings are. This requires bringing stakeholders together and mediating their disputes.

### **Conclusion: Starting the Conversation**

To my knowledge, this is the first consideration of convening power as it relates to the work of ethics committees. In retrospect, I am not sure how we missed its central role in clinical ethics. I hope this essay starts a conversation about convening, ethics consultation, and committee work. As organized bioethics moves towards the certification of individual ethics consultants [10, 11], it is important that we do not overlook the *institutional* convening power of ethics committees from which the authority of *individual* consultants derives. In institutional life, in which clinical ethics may seem to be outside the usual corridors of power of hospital administrators and departmental chairs, it is important to appreciate the power of consultation stemming from its ability to convene. For too long, this source of power has been unrecognized by those who engage in ethics consultation or study the structure and function of ethics committees in modern health care. It is time that the bioethics community *gather together* to better apprehend the role that convening power plays in ethics consultation and how it shapes the broader policy and educational functions of ethics committees.

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## HISTORY OF MEDICINE

### Why Did Hospital Ethics Committees Emerge in the US?

Mark P. Aulisio, PhD

Ethics committees are the primary mechanism for dealing with ethical issues in hospitals in the United States today [1-3]. Present in nearly every US hospital, ethics committees were virtually nonexistent in the 1960s and '70s and, as recently as the early 1980s, were present in only 1 percent of US hospitals [4]. By the late 1980s, however, ethics committee presence had expanded to over 60 percent of US hospitals [5]—a figure that jumped to over 90 percent by the late 1990s [6], when ethics consultation services (a standard function of ethics committees) were present in all US hospitals with 400 beds or more, federal hospitals, and hospitals that are members of the Council of Teaching Hospitals [2].

Why did ethics committees come to be present in nearly all US hospitals in the span of a few short decades, beginning in the 1970s? To answer this question, I will (1) consider the [historical emergence](#) of ethics committees in the US, highlighting just a few of the landmark events that contributed to their rise; and (2) glean from these events key underlying features of the need that ethics committees arose to address.

#### The “God Committee” (1962)

In order to understand the rise of ethics committees in the US, we need to reach back to at least the 1960s when Belding Scribner, at Swedish Hospital in Seattle, made possible dialysis as we know it by building on the work of the Dutch physician Willem Kolff. In the 1940s, Kolff had created the first dialysis machine by modifying an automobile fuel pump to circulate blood outside of the body to be filtered through a series of tubes and then returned back to the body. The problem with Kolff’s device was that each artery and vein could be used only once, giving patients a limited number of opportunities for dialysis. Scribner developed a permanent indwelling shunt with a shut-off valve that allowed for repeated dialyzing through the same sites, thus extending patients’ lives indefinitely [7]. Over time, Scribner recognized this benefit and convinced hospital administrators to establish 17 outpatient dialysis slots in a long-term “Artificial Kidney Center” [7]. As word of Scribner’s breakthrough spread, the number of candidates for dialysis at Swedish Hospital grew dramatically, far outstripping the Artificial Kidney Center’s capacity to provide dialysis for all of them. The stunning success raised a profound ethical question: How should candidates for dialysis be chosen [8]?

To address this question, Scribner appointed an “[Admissions and Policy Committee](#)” that was composed of lay people whom he considered to be representative of the community (e.g., a minister, housewife, lawyer, banker, labor leader, and state government official) and a surgeon and charged it with formulating nonmedical criteria for the selection of dialysis candidates [9]. The group considered a candidate’s age, sex, occupation, marital status, education, dependents, income and net worth, past performance and future potential, and references [7, 9]. Scribner’s account of the committee at a major media convention to raise awareness about the dialysis breakthrough became the focus of a front-page article in the *New York Times*, precipitating a firestorm of controversy. The criteria adopted by the committee soon came to be viewed pejoratively as passing judgment on candidates’ “social worth,” and the committee itself was infamously dubbed the “Seattle God Committee” [10].

How *should* candidates for dialysis be selected? To Scribner’s credit, he realized that, aside from a few obvious medical exclusion criteria, there was no strictly medical or scientific answer to this question [11]. Indeed, Scribner saw that any answer to the question would be fundamentally value-laden or value-dependent in a way that the question of who *needed* dialysis was not. While the God Committee was not the first ethics committee as we now conceive of such committees, we can see in the impetus for its creation many key features of the need that ethics committees later emerged to address: technology creating options that formerly seemed unthinkable, value-laden questions that go well beyond what medical science can address, a pluralistic context in which not all involved share the same values, and the need for decisions to be made in a relatively short timeframe.

### ***In re Quinlan (1976)***

A host of other very [public controversies](#) in the 1960s through the early ’70s helped make health professionals, the general public, and policymakers alike aware of the need for some way to address ethical issues in biomedicine [12-14]. Nevertheless, there is arguably no case that more poignantly illustrated that need than the tragedy of Karen Quinlan [15]. On April 15th, 1975, 21-year-old Karen Quinlan was found unconscious and nonresponsive by friends not long after they helped her to bed. Ms. Quinlan, who suffered from a drug overdose, was transported to Newton Memorial Hospital, placed on a respirator, and later transferred to St. Clare’s Hospital in Denville, New Jersey, where she remained in a [vegetative state](#), fed through a nasogastric tube. After months of hoping against hope, Karen’s parents, Joseph and Julia Quinlan, in consultation with family and their parish priest, came to accept that their daughter was not going to regain consciousness and therefore to believe that she would not want to be kept alive on the respirator. When the Quinlans requested that their daughter be taken off the respirator and allowed to die, hospital administrators and the physicians responsible for her care refused the request on the grounds that to do so would be euthanasia—in their eyes, a form of murder. To be fair, we need to acknowledge that this position was no different

from that of the American Medical Association (AMA) at the time and that withdrawing (as opposed to withholding) life-sustaining respirator support was far from standard practice [7].

Appealing to the constitutional right to privacy, the New Jersey Supreme Court ultimately supported the Quinlans' right to have respirator support withdrawn on their daughter's behalf. Karen Quinlan's plight, however, shook the general public in a way that would be hard to overstate. As the philosopher Gregory Pence eloquently put it, together the "invasive feeding tube and the respirator...would come to symbolize an oppressive medical technology, unnaturally prolonging dying" [16]. Like the God Committee, the Quinlan case highlights many of the features of the need that ethics committees emerged to address: technological developments creating options that formerly seemed unthinkable, value-laden questions and decisions that go beyond what medicine or science itself can address, the fact that not all involved share the same values, and the time-pressured need for decisions. Unlike the God Committee, however, the Quinlan case had very broad resonance, as nearly anyone could easily imagine him- or herself in the same position as Joseph, Julia, or Karen Quinlan. The New Jersey Supreme Court, apparently motivated in part by the fear of a torrent of cases that would grind the judicial system to a halt, suggested that "ethics committees" (meaning, albeit, mostly physician-dominated prognosis committees) might play an advisory role in such cases as an alternative to the courts [17].

### **From Doe Regulations to Ethics Committees (1980-'86)**

After *Quinlan*, additional events spurred the development of ethics committees. The early '80s witnessed the divide between pro-life and pro-choice views after *Roe v. Wade* [18] extend into a debate around withholding or withdrawing treatment for severely impaired newborns, resulting in the Baby Doe regulations [19], which required aggressive care for newborns unless such care:

would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant [20].

By the end of 1984, the American Academy of Pediatrics [21] and the American Hospital Association [22] issued statements supporting the use of interdisciplinary ethics committees as an alternative to governmental investigation in such cases, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed the establishment and use of ethics committees in hospital settings in its influential report, *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions* [23]. Two years later, the AMA Council on Ethical and Judicial Affairs also supported their use as a way of addressing ethical issues that emerge in clinical settings [24]. In this context [25], the

dramatic growth of ethics committees from around 1 percent in the early 80s to over 60 percent of US hospitals by the late 1980s is both remarkable, because of the short timeframe, and understandable, given the growing recognition of the need [4, 5].

### **The *Cruzan* Case (1990)**

We conclude with the case of Nancy Cruzan, a Missouri woman who had been injured in a car accident in 1983 at the age of 24 and remained in a permanent vegetative state seven years later. Unlike Karen Quinlan, who was kept alive by both a respirator and a feeding tube, Nancy Cruzan was kept alive only by a feeding tube—an example of technological developments creating new dilemmas that, as we have discussed throughout, ethics committees arose to address. Nancy Cruzan’s parents, Joe and Joyce Cruzan, requested that the feeding tube be withdrawn and that she be allowed to die, on the grounds that Nancy would not have wanted it [26]. Opposed by the State of Missouri—in the type of value-laden conflict characteristic of these cases emerging in a pluralistic context—the case made its way to the US Supreme Court and was finally decided in 1990 in the Cruzans’ favor. The legal issue in the initial case was whether the State of Missouri had the right to set the evidentiary standard regarding the wishes of an incompetent patient to have a treatment withdrawn. Missouri had set a “clear and convincing evidence” standard and argued that Joe and Joyce Cruzan had failed to meet it in offering only vague recollections of their daughter’s wishes [7]. The Supreme Court’s subsequent decision, however, recognized that competent patients have a constitutional *liberty* interest, i.e., a constitutional liberty-based right, to be free of unwanted medical interventions [26].

More than 25 years later, it is easy to forget that the State of Missouri actually won the case, in a decision that was roundly criticized by many bioethicists at the time [27]. In the immediate aftermath, the significance of the decision in furthering patients’ rights was much harder to see because the Supreme Court majority opinion favored Missouri and, therefore, ostensibly left Nancy imprisoned by medical technology. Interestingly, not long after its victory, the State of Missouri claimed to have discovered additional evidence of Nancy Cruzan’s wishes (allegedly, people came forward who knew her by her married name, Nancy Davis, and provided additional evidence of her wishes not be kept alive in these circumstances as Karen Quinlan had been) and moved to have the feeding tube withdrawn [7].

Given the State of Missouri’s victory, why was the Cruzan case a major victory for patients’ rights, and how did it contribute to the rise of ethics committees? As noted above, *Cruzan* recognized that a *competent* patient has a constitutional right to be free of unwanted medical interventions [26]. Once competent, but now incompetent, patients, then, also must have such a right, raising the question of how that right might be respected. In her concurring opinion, Justice Sandra Day O’Connor emphasized that the task of crafting protections for the liberty interests of such patients is entrusted to the

“laboratory of the states” [28]. Public outcry during and after the Cruzan case led directly to the passage of the Patient Self-Determination Act (PSDA) of 1991, which underscored patients’ rights to direct their care by mandating, among other things, that patients be informed of such rights and offered information about advance directives [29, 30].

For our purposes here, the final push in the emergence of ethics committees in the US came in 1992, when the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) changed its *recommendation* that hospitals have some “mechanism” for dealing with ethical issues in clinical care to a *requirement* [31]. It would appear to be no mere coincidence that the process for initiating this change came on the heels of the very public discussion of the Cruzan decision and the passage of the PSDA. Not surprisingly, the 1990s saw the presence of ethics committees in US hospitals jump from 60 percent to over 90 percent by the end of the decade [6].

### **Conclusion**

These three cases—the God Committee, Quinlan, and Cruzan—all feature the technological developments, value-laden questions, clashes between values in a pluralistic context, and relative time-pressure for decision making that I argue characterize the need that ethics committees came into existence to address—a need that seems unlikely to abate in the foreseeable future.

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## SECOND THOUGHTS

### Hospital Ethics Committees, Consultants, and Courts

George Annas, JD, MPH, and Michael Grodin, MD

Hospital [ethics committees](#) grew out of legal controversies regarding the refusal of life-sustaining treatment. We review the fragmented history of hospital ethics committees and argue that though they were born of concerns about legal liability, they do best when they [stick to clinical ethics](#) and leave legal questions to a hospital's attorney and the courts. We also underline that procedural mechanisms, including ethics committees and [advance directives](#), have not had a measurable role in improving end-of-life care or reducing end-of-life treatment conflicts.

#### The Karen Quinlan Case and the Emergence of Institutional Ethics Committees

A famous hospital ethics committee, and the one that began the movement for hospitals to have ethics committees, was instituted by the New Jersey Supreme Court in 1976 in the case of Karen Ann Quinlan [1]. The court determined that Ms. Quinlan, who was in a persistent vegetative state, had a constitutional and common-law [right](#) to refuse treatment, even if the refusal would result in her death. Nonetheless, her physicians were unwilling to remove her from a ventilator unless they were reassured that they could not be sued for this action. The court was sympathetic to the physicians and ruled that if a hospital ethics committee agreed with their prognosis—that there was “no reasonable possibility of Karen returning to a cognitive, sapient state” [2]—the physicians would be immune from any legal liability for removing her ventilator at her parents' request. The court had two desires: to help the Quinlans end invasive and unwanted treatment of their daughter and to discourage physicians and hospitals from taking their conflicts with patients outside the hospital for courtroom resolution. The court's ruling, unique among all other state courts that have heard similar cases, permitted hospital ethics committees in New Jersey to grant physicians legal immunity based on a prognosis determination [3].

Similar “right to die” decisions were handed down by courts in other states—but not the immunity-granting authority the New Jersey court bestowed on its ethics committee [4]. Not only did no other state grant ethics committees this authority, but even in New Jersey, the Quinlan-styled “ethics committee” was renamed a “prognosis committee” (because its real charge was to make a prognosis determination) with membership limited to neurologists and neurosurgeons [5]. Nonetheless, some hospitals liked the general idea of using an ethics committee to help resolve conflicts and keep them out of court. Although hospital ethics committees can't grant legal immunity, an expert

committee's agreement that a proposed resolution of a conflict is consistent with good clinical practice means that the likelihood of a successful lawsuit approaches zero. On the other hand, although most ethics committees are advisory only and don't make decisions for physicians, at least some physicians we have worked with feel that it is extremely difficult for them not to take the "advice" of this committee (assuming the committee has experts on clinical ethics, clinical practice, and hospital policies), because it could open them up to a lawsuit if the patient is made worse off by their nonconforming actions. This might inhibit some physicians from seeking help from the ethics committee in the first place—at least those who believe that clinical-ethical decisions should be made in the context of physician-patient relationships and that resort to a committee could do more harm than good. This is because whenever a physician requests a consultation, the working assumption is that expert help is needed and the advice of the expert will be followed (at least if not following the advice cannot be satisfactorily explained by the physician in the health record).

### **Other Related Committees**

Other types of ethics committees had been formed to oversee nontherapeutic activities in hospitals, most notably human subjects research. Research by physicians on their patients (and on nonpatients) had been associated with use and abuse of human subjects as means to an end, because the research context was a nonfiduciary one: research was being done to gain generalizable knowledge to benefit society and there was potential for significant harm to the patient/subject. In the mid-1960s (about a decade and a half before the Quinlan case), Congress recognized that a new and independent mechanism was needed to protect human subjects, which led to the federal government's creation of what is now known as the institutional review board (IRB) in 1974 by the National Research Act [6–8]. Unlike an ethics committee, an IRB is required by federal law and bound by a set of federal regulations that determine the scope of its authority (limited to human subjects research) and set criteria for its deliberations and decisions—specifically, determining that the risks of a proposed experiment are less than the expected benefits and requiring that informed consent is obtained [9].

Around the time of the Quinlan case, another type of ethics committee, the abortion committee, was being abandoned. The abortion committee, required by some hospital policies, was a group of physicians whose concurrence was required before a physician could perform an abortion. In the 1973 opinion of *Doe v. Bolton* (a companion to *Roe v. Wade*), the US Supreme Court decided that this was an unconstitutional interference with the rights of pregnant women and their physicians and that the concurrence of other physicians could not be a requirement for all of physicians' treatment decisions—the state could require medical licensure, but not the concurrence of a committee of physicians, prior to the performance of a medical procedure [10]. Abortion remains the most politically controversial medical procedure, but the *Doe v. Bolton* ruling against committee approval has never been challenged.

In the early 1980s, the American Academy of Pediatrics recommended that all hospitals with neonatal intensive care units establish “infant bioethics committees” to advise on the treatment of infants with severe disabilities. This was in response to, and intended to be a substitute for, the Reagan Administration’s “Baby Doe” regulations concerning the nontreatment of newborns with disabilities such as Down syndrome. The administration’s rules were ultimately thrown out in court because the courts found that making treatment decisions for newborns with disabilities—and the even more complicated premature newborns—was properly classified not as possible child neglect (a state law issue) but rather as a complicated judgment best left in the hands of a child’s parents with the guidance and approval of the child’s physician [11]. In our view, no further progress has been made in this area, although hospitals with major neonatal intensive care units continue to have ethics committees to provide advice on request. (We have both served on such committees.)

### **The Contemporary Institutional Ethics Committee**

Post-Quinlan institutional ethics committees (IECs) were initially formed to deal with adults in critical care [4] and focused frequently on do-not-attempt-resuscitation (DNAR) orders—previously known simply as DNR or do-not-resuscitate orders—the right to refuse treatment, determination of death, and organ transplant issues. Often the committees helped a hospital develop written policies and procedures concerning these issues. Subsequently, especially in large safety net hospitals like the one we work in, disputes have become more often centered on conflicts caused by a disagreement between patient or family and the clinical team about demand for treatment judged to be nonbeneficial or even harmful. This is sometimes called the “[futility problem](#),” although we think it is mostly a communications problem compounded by unrealistic expectations on the part of a patient’s family.

Ethics committees continue to exist and, in our experience, deal mostly with end-of-life conflicts and policies. Nonetheless, the nature, membership, scope, limits of authority, and accountability of institutional ethics committees have still not been well established. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), for example, requires some mechanism for ethics review but doesn’t specify what it must entail [12]. By contrast, an IRB derives its authority and mandate from specific federal regulations, which it is required to follow. Although the legal liability rationale for IECs has faded into the background, it is still worth recalling that, at IECs’ birth, a committee of the American Hospital Association recommended that IECs all have at least three lawyers as members: one to represent the hospital, one to represent the IEC itself, and an independent lawyer to give the committee neutral advice (William Curran, personal communication). It was also suggested that, since the ethics committee is primarily a procedural mechanism to resolve disputes, a procedural expert (i.e., a lawyer) should act as the committee’s chair. Thankfully (in our opinion) this view has not prevailed. Although ethics committees may

well resolve specific disputes, they act best, we think, as substantive policymakers and education resources. They should not act as part of “risk management”—that’s the job of the hospital’s legal team.

In our experience, it seems fair to conclude that, over the past decade, IECs have been primarily involved in four activities. Three are uncontroversial: education about clinical ethics (which does not require a committee); assistance with developing and implementing policies such as end-of-life care, drafting of DNAR order policies (when it is helpful to have a multidisciplinary committee), and assistance with determinations of brain death; and retrospective review of complicated cases reflecting systemic problems and requiring policy changes. The fourth activity can be controversial because it can seem to be setting the committee up with decision-making authority. This activity involves ethics committees’ prospective review of ongoing cases, which requires a consultation mechanism or subcommittee meeting rather than the convening of an entire committee, as the cases are ongoing (i.e., a process similar to consultation liaison psychiatry).

Ethics committees continue to evolve, as do the nature of the cases and conflicts they are asked to help resolve. In our opinion, two main types of conflicts predominate today, both focusing on end-of-life care conflicts. We strongly believe that the vast majority of what are framed as ethical disputes are more accurately understood as problems of communication and group dynamics and can best be addressed by standard conflict resolution processes, including listening to the patient and the patient’s family. In our experience, communications problems are much more readily resolved by an ethics consultant leading a discussion with all of the clinical personnel involved in a particular decision, rather than by taking those problems to a committee for discussion. Of course, because ethics committees are not on duty 24 hours a day (though some have members who are on-call for ethics consultation) and, like other hospital committees, meet regularly—once a month being a common schedule, in our experience—only a representative or two of the committee can help in real-time conflict resolution, usually through a mechanism like a “clinical ethics consultation service.” The cases to which such a service is most likely to be called for help are those in which there is either no family member available or the family is demanding continued treatment that clinicians no longer believe is [indicated or beneficial](#) (just the opposite of the *Quinlan* case, which started it all).

Our experience with ethics consultations and ethics committees in a large urban safety net hospital leads us to conclude that those that are difficult to resolve present no clear-cut answers. As one of us (MG) has put it, “difficult cases are difficult because they are difficult.” This seeming tautology can be helpful to both physicians and families in beginning to tackle an ethics problem, the discussion of which can usefully be opened by trying to identify why people are uncomfortable with making treatment decisions. While

almost all ethics committee questions involve end-of-life decisions, those that also involve the poor, disenfranchised, culturally different, and friendless are especially difficult in a culture that both marginalizes these groups and valorizes autonomy. This makes decision making even more challenging in the context of a poor neurological prognosis and when the patients themselves are not competent to make their own decisions (the original *Quinlan* problem, which is still with us).

The movement to get everyone to articulate their directives for end-of-life care, and to appoint a health care agent to make decisions for them when they are unable to make them themselves, is all to the good. Nonetheless, forms and committees will never be able to prevent all clinical controversies at the end of life, because these reflect substantive views on death and how much should be done to delay it. It is at least discouraging that after 40 years of hospital ethics committees, the way we die in hospitals continues to be recognized, both by major medical groups like the Institute of Medicine and popular medical writers such as Atul Gawande, as a major scandal necessitating major overhaul [13, 14]. Ethics committees cannot solve all the problems of death and dying in hospitals, but we think they have a constructive role to play in helping to develop policies and educate clinicians in ways that are likely to promote both patient rights and good health care.

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