Role of the Ethics Committee*

Helping To Address Value Conflicts or Uncertainties

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This article addresses two basic questions about ethics committees: why we have them, and how they might be helpful to clinicians. Our answer to the first question is twofold. First, we suggest that legal, regulatory, and professional forces drove the development of ethics committees, particularly as an alternative to litigation. Second, we argue that ethics committees arose in response to a clinical need for a formal mechanism to address some of the value conflicts and uncertainties that arise in contemporary health-care settings. We argue that this need, reflected in early high-profile legal cases, stems partly from the complex value-laden nature of clinical decision making, a pluralistic societal context, a growing recognition of the rights of individuals to live by their values, and the relevance of those values for medical decision making. In answer to the second question, we draw out three ways ethics committees might be helpful to clinicians: education, policy formation or review, and consultation. We devote the majority of our discussion to ethics consultation and its relation to the emerging area of palliative care. In so doing, we highlight three important differences: (1) the scope or range of cases for which they may be appropriate, (2) focus in any particular case, and (3) general orientation—between ethics consultation and palliative care that clinicians should take into account in deciding to seek the assistance of either or both.

Key words: education; ethics committees; ethics consultation; palliative care; policy formation/review, role of

As recently as 1983, only approximately 1% of US hospitals had ethics committees.1 By 1989, the number had grown to > 60% and to > 93% by 1999.2,3 Currently, all US hospital accredited by the Joint Commission on the Accreditation of Health-care Organizations are required to have a mechanism for addressing ethical issues, and a recent study4,5 found that all US hospitals with ≥ 400 beds, federal hospitals, and those that are members of the Council of Teaching Hospitals have a process for ethics consultation. In addition to this relatively sudden proliferation of ethics committees in US hospitals, ethics committees are increasingly common in other health-care settings such as long-term care and even home care. Outside of the United States, clinical ethics committees are at least as prevalent in Canada as they are in the United States, and their presence is growing in Europe, much of Asia, and Central and South America.6,7 In this, the sixth installment in the CHEST “Ethics Primer” series, we focus on ethics committees: why we have them, and how they might be helpful to clinicians.

Why Do We Have Ethics Committees?

Historically, highly publicized cases such as those of Karen Quinlan (1976), the Baby Doe cases...
Mrs. Jones, a 44-year-old white woman, presents in the emergency department for treatment of a sprained wrist. She is taken to a treatment room for care. About 10 min later, she is found lying on the floor of the emergency department treatment room unconscious. It is determined that she has suffered a cardiac arrest, and resuscitative efforts are undertaken. After 25 min, she is revived, placed on ventilator support, and taken to the medical ICU, where it is subsequently determined that she is neurologically devastated, although not technically “brain dead.” After several weeks, she is septic with multisystem organ failure. Her husband, mother, and 20-year-old son (from another marriage) have visited her daily. They are very upset and do not understand how this could have happen “in a hospital.” Mrs. Jones’ husband is especially angry and is threatening legal action. When approached about his wife’s code status, he insists that “everything be done” and warns the attending physician not to “pull the plug on any of those machines.” Later, he confides to one of the nurses that he believes his wife will “wake up” and he does not believe that there is “anything really wrong with her brain.” He also says that removing her from the ventilator would be “killing” her. The care team believes that it is now delivering “futile” care and thinks the patient should be made “do not resuscitate,” with comfort measures only. They strongly object to performing cardiopulmonary resuscitation on the patient should she arrest. In contrast to Mrs. Jones’ husband, her mother and son appear to understand the diagnosis and agree with the recommendation of the team to discontinue ventilator support. The social worker reports that they “don’t think the patient would want to be kept alive like this.” They also ask about whether her organs might save someone’s life and, if so, what they would need to do to donate her organs.

Unfortunately, the case of Mrs. Jones is probably all too familiar for the readers of this journal. Advances in medical technology have created options that were almost unthinkable just a half century ago. Mrs. Jones, like Karen Quinlan before her, is alive only because of life-saving technologies like ventilator support, nasogastric nutrition, and broad-spectrum antibiotics that make it possible to maintain her indefinitely. Technologic advances have likewise made organ donation possible and increasingly frequent, hence the inquiry of Mrs. Jones’ son and mother. Interestingly, many of these same advances in medical technology have also contributed to the public perception, reflected in the words of Mrs. Jones’ husband, that medicine can cure all and that things like this can’t happen in the hospital without someone having made a mistake or being at fault in some way.

In addition to the sometimes very difficult options posed by advances in medical technology, clinical decision making is further complicated by a number of other factors. For patients like Mrs. Jones, various
service lines and specialties will be involved in care, adding layers of complexity to even basic communication with family and impeding their understanding. In many teaching ICUs, for example, residents come and go, nurses change frequently, attendings rotate every few weeks, and a variety of subspecialists and fellows will be intermittently involved in care. At the same time, family members are often struggling with a sense of loss, grief, and questions of purpose and meaning. Similarly, as we see in the case of Mrs. Jones, interpersonal dynamics between family members themselves may be confusing, tangled, and strained.

In the midst of all of this, clinical decision making must go on, and that decision making is fundamentally value laden. What does this mean for those involved in the case of Mrs. Jones? It means, at the most basic level, that decisions about quality of life, whether longer life is “better” come what may, about withholding or withdrawing life-sustaining or life-saving treatments or interventions, about whether or not to donate organs, and under what circumstances are largely, even if not solely, value dependent. It also means that even if there is complete agreement about the medical facts of Mrs. Jones’ case, her diagnosis and prognosis, even to the point of prognostic certainty, there will not be agreement about what should be done and why unless all concerned share the same values and interpret the relevance of those values for the situation in the same way. To put it differently, medical science cannot tell us whose values or which values should drive these types of decisions, or what any given set of values might mean for the case at hand.

Finally, this complex value-laden clinical decision making goes on in a clinical context that reflects the broader pluralistic societal setting and must respect the moral and political rights of individuals to live according to their (sometimes very different) values. As we have argued elsewhere, neither patients, families, and surrogates, nor health professionals themselves have to check their personal moral values at the door of the hospital when entering. Instead, each retains a moral and political right to live by his or her own values, a right that must be respected in health care as in other settings. It is these two broader societal features, reflected in the clinic, coupled with the highly complex value-laden nature of clinical decision making characterized above that creates the need for ethics committees (or something like them) in contemporary health-care settings. When complex value-laden decisions involve a wide variety of people who do not share the same values but who each have a right to live by their values, value conflict or uncertainty is inevitable. Thus, a second answer to the question of why we have ethics committees is, in short, that we need them to help us deal with value conflicts and uncertainties that inevitably arise in contemporary medical practice.

**How Can Ethics Committees Be Helpful to Clinicians?**

Ethics committees can be helpful to clinicians in addressing value conflict or uncertainty as it arises in their practices primarily through a threefold function of ethics education, policy formation and review, and ethics consultation. Just how helpful any ethics committee may be in each of these areas will depend primarily on the strengths and weaknesses of the ethics committee in question and the needs of the local institution. It is incumbent on ethics committees to make their primary functions known to their constituent communities, but it is also incumbent on health professionals to familiarize themselves with the educational, policy formation/review, and consultation functions of their local ethics committees. Although each of these is important, we will devote the majority of our attention to ethics consultation as it is likely to be the most relevant for the readers of this journal. In so doing, we will draw out the possible relationship between ethics consultation and palliative care that increasingly is involved in the types of cases *CHEST* readers might bring to consultation. Before turning to this, we briefly consider education and policy formation/review in turn.

**Education**

Ethics committee educational efforts should include self-education, education of health professionals and staff, and community outreach. Self-education is the most important of these, at least initially, as it is necessary, if education for health professionals and the broader community is to be done well. In addition, the two other functions of ethics committees—policy formation and review, and ethics consultation—require sustained ongoing ethics education for members. Not surprisingly, then, a 1999 study indicated that ethics committees spend the highest percentage of their efforts on “self education.” This is particularly important given that ethics committees are staffed primarily by health professionals and others who have had little or no formal training in either clinical ethics or conflict resolution. A growing number of resources are available for ethics committee members to better prepare them to carry out their responsibilities. For example, the American Society for Bioethics and Medical Humanities’ Clinical Ethics Task Force has drafted a
Educational resource entitled *Improving Competence in Ethics Consultation: A Learner’s Guide* that is now available in draft form and should soon be available in final form. This educational tool includes learning objectives, strategies, and a wide range of resources for three basic domain areas for clinical ethics consultation: knowledge, skills, and responsibilities. In addition to availing themselves of these types of resources, we strongly recommend that ethics committee members participate in any clinical ethics networks or bioethics centers or departments in their region that offer continuing ethics education.

Educational outreach offered by ethics committees will, of course, vary from institution to institution; however, basic issues in clinical ethics such as informed consent and refusal, decision capacity (competence), confidentiality and privacy, minors and decision making, and a host of issues related to end-of-life decision making (withholding/withdrawing life-sustaining treatments, “futility,” do not resuscitate) to be relevant across a broad spectrum of health-care institutions and for a wide variety of practitioners. In addition, educational outreach should ideally include institution-specific efforts that target particular needs. For example, ethics committees at our institutions have put together educational programming ranging from short 20- to 30-min “in services” to full-day conferences on topics such as dealing with the chronically nonadherent patient, the role of personal values in professional life, medical mistakes, ethical issues in perinatal medicine, and organ donation and transplant.

In our view, education is ultimately the most important function of an ethics committee because the majority of ethical issues in clinical medicine will always be handled by clinicians involved in delivering care rather than by ethics consultants or committees. While sensational or headline-grabbing ethical issues are rare, issues of privacy, respect, confidentiality, informed consent, and truth telling confront clinicians on a daily basis. An ethics committee will have the largest impact on the “ethics” of an institution by raising health-care providers’ awareness of and ability to address these issues.

**Policy Formation and Review**

The second area in which ethics committees might be helpful to clinicians in addressing value conflict or uncertainty as it arises in their practices is policy formation and review. Like educational efforts, efforts to form or review policy will vary from ethics committee to ethics committee, and according to the nature of the institution the ethics committee serves. For example, an ethics committee at a major academic medical center may have input on policies governing informed consent, confidentiality and privacy, end-of-life decisions (e.g., advance directive and life-sustaining treatment policies), brain death, organ donation and transplant, disclosure of medical mistakes, and more. In addition to these more traditional ethics policy areas, ethics committees at our institutions have formed or reviewed policies or guidelines on issues as common as dealing with chronic patient nonadherence to those as obscure as surrogate parenthood and posthumous sperm procurement. Policy development can set the standards for care for patients at the hospital as well as provide guidance for health providers when they face unusual or especially problematic issues.

Ethics committees are sometimes asked to give input on organizational ethics issues as well, especially when these issues may have an impact on patient care. Indeed, Joint Commission on the Accreditation of Healthcare Organizations ethics standards now extend to organizational ethics issues (e.g., marketing, billing, financial incentives for clinicians, and so forth) and emphasize the growing interdependence of patient rights and organizational ethics.

**Ethics Committees, Ethics Consultation, and Palliative Care**

Ethics consultation, whether done by committees, small teams, or individuals, is the function of ethics committees that directly engages the clinical need that, as we argued above, drove their development in the first place: a need for a formal mechanism to address some of the value conflicts and uncertainties that arise in contemporary health care settings. We argued that this need, reflected in early high-profile legal cases, stems partly from the complex value laden nature of clinical decision making, a pluralistic societal context, and a growing appreciation of the rights of individuals to live by their values and the relevance of those values for medical decision making.

As noted above, palliative care is increasingly involved in the kinds of cases that *CHEST* readers might bring to ethics consultation. Ten years ago, few hospitals had palliative-care services. However, the number of palliative-care programs increased from 5% of hospitals in 2000 to 25% of hospitals in 2003. Larger academic hospitals as well as those with critical care beds are more likely to have palliative-care programs. For example 50% of hospitals with > 250 beds have a program and 75% of the members of Council of Teaching Hospitals have programs.

There is a great deal of overlap between palliative care and ethics consultation. Our anecdotal experience is that many palliative-care professionals also...
have training in clinical ethics. Many palliative-care services spend a great deal of their time focusing on "big picture" issues such as setting goals of care in light of patient values and within the limits of medical appropriateness. Palliative-care services have also devoted their attention to ICU-based end-of-life cases, which remain one of the single largest category of cases brought to ethics consultation. A number of studies affirm the potential benefits of both ethics consultation and palliative care particularly in ICU settings. These benefits include higher levels of patient satisfaction, shorter length of stay and more "appropriate" transition from "cure" to "comfort" modes of care.

How and whether these benefits are best realized through ethics consultation, palliative care, or both is unclear. In much of the literature, other than the fact that palliative-care service also provides symptom management, it is often hard to distinguish between the ethics consultation and palliative care. The usefulness of either ethics consultation or palliative care for CHEST readers will be contingent on a number of factors, not the least of which are the unique features of the case with which they are confronted, and the strengths and weaknesses of the respective services at their institutions. This being said, in our view, the failure of the literature to distinguish ethics consultation and palliative care is unfortunate because there are significant differences in the general orientation and expertise of most palliative-care and ethics consultation services that are important for practitioners to take into account as they decide whether to seek the assistance of either or both in any particular case.

A major report of the American Society of Bioethics and Humanities, Core Competencies for Health Care Ethics Consultation, defines ethics consultation as "...a service provided by an individual or a group to help patients, families, surrogates, health care providers, or other involved parties address uncertainty or conflict regarding value-laden issues that emerge in health care." That same report characterized a now widely accepted model for ethics consultation, "ethics facilitation," as helping to identify and analyze the nature of the value uncertainty and then facilitating the building of consensus among involved parties within the range of morally acceptable options.

Viewed in this way, the general orientation of ethics consultation focuses on ethical analysis, broadly construed as identifying and analyzing value conflict and uncertainty, and facilitation toward the end of building a consensus among parties to the case concerning which of the morally acceptable options should be pursued. This requires expertise in information gathering (to get a clear picture of the "facts" of the case); conceptual clarification/analysis (eg, "confidentiality," "surrogate," "substituted judgment," "best interest"); normative analysis (eg, implications of societal values, ethics, institutional policy for the case; assisting individuals in clarifying their own values and their implications for the case; identifying ethically acceptable shared commitments); and facilitation or mediation (eg, dispute/conflict resolution, consensus building).

Palliative care, however, is typically defined as "comprehensive" or "holistic" care. For example, the American Academy of Hospice and Palliative Medicine position statement on palliative care asserts that palliative care involves "effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s). Evaluation and treatment should be comprehensive and patient-centered, with a focus on the central role of the family unit in decision-making." Consonant with this view, palliative care is now widely regarded as the comprehensive management of physical, psychosocial, spiritual, and existential needs of patients (and families) facing a life-limiting illness. Palliative care, therefore, employs what we have elsewhere termed a comprehensive care model. As such, palliative-care teams should have expertise in a variety of areas including the medical management of physical symptoms like pain, dyspnea, nausea, and vomiting, the recognition and treatment of psychological issues such as delirium and depression; helping patients and their families negotiate the goals of care; and helping patients and their families address spiritual or other existential needs. Because of its comprehensive orientation and required range of expertise, palliative-care teams may include members from medicine, nursing, social work, pastoral care, nutrition, rehabilitation, pharmacy, and other professional disciplines.

The definitions, orientations, and attendant expertise for both ethics consultation and palliative care suggest some important differences between them that should be taken into account by clinicians in deciding to involve either or both in any particular case. Although a detailed discussion of these differences would take us well beyond the scope of this article, there are three salient points of relevance for CHEST readers. First, the range of cases that may be appropriate for ethics consultation is much broader than that of palliative care. To put it simply, value conflicts or uncertainties emerge even when patients are not faced with life-limiting illness or in need of palliative measures. Second, even as the scope of cases appropriate for palliative care is...
narrower than that of ethics consultation, its focus in any given case is much broader. Ethics consultation has a relatively narrow focus: addressing value conflict or uncertainty and building consensus among appropriate decision makers about how to move forward in an ethically acceptable way. In contrast, palliative care has a relatively broad focus: the holistic management of patient and family needs in the face of life-limiting illness or the need for palliative measures. Finally, palliative-care teams, on the “comprehensive care provider” model, become involved in cases primarily as medical “insiders” and are likely to be perceived as such. In contrast, those doing ethics consultation, on the “ethics facilitation” model, are not care providers who then become members of the care team; rather, they remain essentially “outsiders” and are likely to be perceived as such. What does this mean?

When palliative-care teams become involved in a case, they do so as members of the care team or even as an alternative care team. The palliative-care team is being asked to provide their expertise in the comprehensive care of patients, families, or surrogates. In this respect, palliative-care professionals are no different than other health-care providers dealing with patients, families, or surrogates. While palliative-care teams may bring expertise in defusing conflict situations, clarifying key concepts like the role of a “surrogate” or “substituted judgment,” a palliative-care clinician may also give an opinion on the appropriate medical management of the patient. In this way, the recommendation of the palliative-care team is a second opinion regarding appropriate medical management and delivery of patient care, so much so that palliative-care professionals may actually take over the management of the patient (taking the patient “on service”) in some cases.

In contrast, ethics consultation, as carried out through an ethics facilitation model, assists primary decision makers, i.e., members of the care team, patients, families, and surrogates, in the identification, analysis, and resolution of the ethical issues they face. Those doing the consult do not themselves become involved as primary decision makers or supplemental or even alternate care providers. They are essentially outsiders helping primary decision makers arrive at an ethically justifiable course of action. Their role is to help the clinicians, patients, and families arrive at a decision that optimally respects and promotes the values of the appropriate decision-makers—most often the values of the once competent but now incompetent patient—within the bounds of medically acceptable options. Common challenges in end-of-life cases include disputes between family or surrogates and care teams about demands for care that is deemed to be ineffectual or even harmful (“futile” care) and confusion among care team members and surrogates alike about the proper role of a surrogate decision maker. As perceived “outsiders” and neutral parties, those doing ethics consultation may be better positioned to affirm for families the authority of the care team not to offer treatments that they deem to be medically inappropriate (identifying the range of medically acceptable options), while also clarifying the proper role of a surrogate decision maker and focusing family and care team members alike on that role. Consonant with this, it is important to emphasize that the commitment of those doing ethics consultation is to both patients, families or surrogates, and health-care providers.

What do these differences between ethics consultation and palliative care mean for you when you are confronted by a thorny case that might benefit from the involvement of one or both of these services? First, as noted above, it is imperative that you familiarize yourself with the strengths and weaknesses of the respective services at your institution. Second, it is equally imperative that you be attentive to the particularities of the case at hand as you attempt to answer a few basic questions that should guide your decision:

- Is this a case that falls within the relatively narrow scope of cases appropriate for palliative care (end of life or at least palliation), or is it more suitable to the broader scope of cases appropriate for ethics consultation (value conflict or uncertainty even outside of end-of-life or palliative scenarios)?
- Is this a case that would benefit from the relatively narrow focus on value conflict or uncertainty of ethics consultation, or the broader comprehensive or holistic focus of palliative care?
- What kind of assistance is needed to address the issues in the case (e.g., additional care providers, second opinion, alternate care team, or other “insider” assistance or “outside” facilitator/mediator, narrow focus on value laden issues and so forth)?
- How will the involvement of ethics or palliative care be perceived and received by the patient, family, and/or surrogates (e.g., insiders “ganging up” on family members, a needed and respected expert opinion on palliative measures, unwelcome outsiders, neutral third parties, and so forth)?

**Conclusion**

Our focus in this article has been on two basic questions about ethics committees: why we have
them, and how they might be helpful to clinicians. Our answer to the first question was twofold. First, we suggested that legal, regulatory, and professional forces drove the development of ethics committees, particularly as an alternative to litigation. Second, we argued that ethics committees arose in response to a clinical need for a formal mechanism to address some of the value conflicts and uncertainties that arise in contemporary health-care settings. We argued that this need, reflected in early high-profile legal cases, stems partly from the complex value-laden nature of clinical decision making, a pluralistic societal context, a growing recognition of the rights of individuals to live by their values, and the relevance of those values for medical decision making.

In answer to the second question, we drew out three ways ethics committees might be helpful to clinicians: education, policy formation or review, and consultation. While acknowledging the primary importance of education, we devoted the majority of our discussion to ethics consultation, and its relation to the emerging area of palliative care, because of its direct relevance for readers of this series. In so doing, we highlighted three important differences: (1) the scope or range of cases for which they may be appropriate, (2) focus in any particular case, and (3) general orientation between ethics consultation and palliative care that are important for clinicians to take into account in deciding to seek the assistance of either or both. Ultimately, it is our hope that this primer on role of ethics committees will be helpful to you, the readers of CHEST, as you face the challenges of dealing with the value conflicts and uncertainties that arise in your own clinical practice.

References

