

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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Karel-Bart Celie

MS-2
Columbia University
New York, NY

Kenneth Prager, MD

Director of medical ethics
Columbia University Medical Center
New York, NY

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