

4 The role and legal status of health care ethics committees in the United States

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Introduction

Over a quarter of a century has passed since health care ethics committees (HCECs) in the United States received legal recognition as alternatives to the courts in resolving conflicts related to patient end-of-life care. By the mid to late 1980s HCECs had been established in over half of U.S. hospitals and had received a certain legitimacy in the health care system. Given their age and growth one could characterize them developmentally as emerging from adolescence and establishing themselves in young adulthood. As a result, we might expect that they would have resolved the identity crisis characterizing the adolescent years. Yet, HCECs in the United States remain somewhat amorphous. In part, this may be due to their relative lack of legal status. In most U.S. jurisdictions HCECs remain unregulated and lack homogeneity in structure and operation. To the extent that they share common characteristics, these committees are multidisciplinary in membership and exist to address ethical dilemmas that occur within health care institutions. Early on in the evolution of HCECs, judges, in several judicial opinions, encouraged the development of these committees, and two states adopted statutes or regulations that provided them with legal status. Until recently, however, HCECs in most states have been able to develop in a variety of ways and perform a range of functions with limited legal authority or oversight. In the last few years, a handful of states have passed laws giving HCECs legal authority to make certain kinds of decisions. While these states remain in the minority, HCECs in most states serve a role as a mechanism for "alternative" dispute resolution, particularly in cases involving end-of-life care. This chapter reviews both the history of HCECs in the United States and their legal evolution.

History of health care ethics committees in the United States

HCECs in the United States emerged in response to advances in life-sustaining medical technology and landmark legal cases concerning allocation and use of that technology. A forerunner to HCECs (hospital ethics

committees) was the lay committee established in 1962 at Seattle's Swedish Hospital to decide how to allocate the use of the first community kidney dialysis units. At the time, they were the only dialysis machines available for outpatient treatment in the world. Other life-sustaining technology gaining widespread use in the 1960s and 1970s included cardiopulmonary resuscitation (CPR), long-term mechanical ventilation, and artificial nutrition and hydration ("tube feeding"). Many of the legal cases concerning life and death medical decision making in the 1970s and 1980s involved discontinuing mechanical ventilation or artificial feeding. These cases influenced the formation of HCECs as alternatives to courts in making such decisions. The opinion of the New Jersey Supreme Court in the case of Karen Ann Quinlan was the first to mention the use of ethics committees. In *Quinlan*, Karen Ann's father asked to be given authority to terminate her ventilatory support as she had been in a permanent coma for several years. The Court recommended that each hospital in the state establish an ethics committee composed of physicians, social workers, attorneys, and theologians which would serve to "review the individual circumstances of ethical dilemma[s] and which [would provide] much in the way of assistance and safeguards for patients and their medical caretakers."¹

Ethics committees were given further endorsement in 1983 when the President's Commission for the Study of Ethical Problems in Medicine wrote its seminal report on withholding and withdrawing life-sustaining treatment. In the report, the Commission encouraged hospitals to "explore and evaluate various administrative arrangements" such as ethics committees "for review and consultation" of cases involving termination of life support for patients who lack decision making capacity in order to protect their interests "and to ensure their well-being and self-determination."² In addition, the Baby Doe Regulations, promulgated under the 1985 Amendments to the Federal Child Abuse Prevention and Treatment Act,³ recommended establishment of Infant Care Review Committees in hospitals caring for newborns and use of the committees when considering withholding or withdrawing life-sustaining treatment from a newborn.

Two states also required hospitals to establish HCECs. In 1987, the Maryland legislature enacted the Patient Care Advisory Committee Act requiring hospitals in the state to establish patient care advisory committees.⁴ The law was subsequently amended in 1990 to require that all nursing homes in the state establish or have access to such committees. Also, after the *Quinlan* case, the New Jersey Department of Health mandated that hospitals in that state establish either an ethics committee or prognosis committee as a condition of licensure.⁵

Perhaps the greatest motivation for hospitals to establish ethics committees was the Joint Commission on the Accreditation of Health Care Organizations' requirement in 1992 that, as a condition of accreditation, hospitals have in place a mechanism to resolve ethical dilemmas in patient care.⁶

These recommendations and requirements significantly influenced U.S. hospitals to establish HCECs. The percentage of hospitals responding to surveys conducted by the American Hospital Association indicated an increase in the number of hospitals with ethics committees from twenty-six percent in 1983 to sixty percent in 1985.⁷ By 1998, McGee and colleagues reported that over ninety percent of U.S. hospitals had ethics committees.⁸

Membership of HCECs in U.S. hospitals

Hospital ethics committees vary in size and membership. Studies indicate a range of three to thirty members, with the "typical" size between twelve and sixteen.⁹ Larger hospitals tend to have larger committees.¹⁰ Virtually all HCECs include physicians, nurses, and social workers. Many include hospital administrators or their designees, hospital board members, and clergy.¹¹ There are no definitive data on how many include community representatives, bioethicists, or attorneys. In a study of HCECs in Maryland, Virginia, and the District of Columbia, approximately half of the committees included a community representative but less than half had a lawyer or bioethicist.¹²

The prerequisite of multidisciplinary membership and deliberation calls for HCECs to include a variety of health care professionals as well as lay persons from the community and individuals knowledgeable in bioethics. Opinions about the ideal composition of ethics committees are influenced by attitudes about their process of deliberation. Those who view ethics committees as impartial panels that come to consensus on an issue, much like a jury, place importance on diversity of representation, including community members. Dugan writes, "[b]ecause [HCECs'] core interest is to promote patient care that reflects an interest in ethical values of patients, organizations, and healthcare professions, their expertise is the sort that calls more for breadth than depth of specialized knowledge."¹³ Those who view ethics committees as providing an expert ethical opinion on an issue may place more emphasis on having members with bioethics expertise. However, definitions of "bioethics expertise" vary.¹⁴ Ethics committees have been criticized for having an over-representation of institutional health care providers and under-representation of community members and members with bioethics expertise. Some critics have argued that committees engage in institutional protectionism and are biased in their membership, which is heavily dominated by health care practitioners. In an article in *The Hastings Center Report*, Cohen argued that "[t]he structure of some committees has been designed to protect institutional interests: a few are chaired by legal counsel for the institution; others are composed almost entirely of members of the board who 'have an interest in ethics.'"¹⁵ In addition, many members have no formal training in bioethics or law and simply sit on the committees out of an interest in the area.¹⁶ Others have

also observed how an ethics committee's composition influences its deliberations and how or whether it reaches consensus. In a review of the literature on clinical case consultation, Williams-Jones found that

when the consultant or chair is a physician, the ethics discussion tends to focus on clinical issues, supporting physicians, and returning the treatment and team to "normal" functioning. By contrast, when the consultant is a non-physician ethicist, the consult is more open, interactive, and open to non-clinical issues; patients and family members are also more likely to be involved in the discussion.¹⁷

The role of attorneys on HCECs has been controversial, in particular, the appropriateness of the participation of hospital legal counsel. Some writers have argued that their participation may be clouded by conflicts of interest. Others fear that concerns about law will dominate any discussion and chill analysis of the ethical issues involved.¹⁸ In part, the controversy about the role of lawyers on ethics committees may result from confusion about the role of legal standards in HCEC deliberations and whether HCECs should be providing legal advice. A study of hospital ethics committees in three jurisdictions found that health care providers view providing legal advice on issues related to patient care as a primary role of ethics committees, and a majority of respondents in two of the jurisdictions indicated that their committee was influenced a great deal by the legal consequences of its recommendations.¹⁹

Institutional setting in which HCECs operate

While the large majority of the literature on HCECs focuses on their role and operation in hospitals, HCECs have been adopted by other types of health care institutions including nursing homes, home health agencies, hospices, and managed care organizations (MCOs). A 1997 survey by the American Association of Homes and Services for the Aging (a membership organization of not-for-profit nursing homes) found that sixty-six percent of non-profit nursing homes had established an HCEC.²⁰ A more recent survey by the New York City Long-Term Care Ethics Network of one hundred and twenty-eight nursing homes indicated that the percentage of these facilities with an ethics committee increased from forty-one percent in 1994 to seventy-one percent in 1999.²¹ National statistics on the percentage of hospices or home health agencies that have an ethics committee are not available. Christensen and Tucker, however, see these institutions as poised to confront ethical issues that have, until relatively recently, been the focus of hospital ethics committees. These authors describe several trends influencing the growth of non-hospital HCECs, including declining numbers of hospital inpatients due to technological breakthroughs, incentives to contain costs, and increased acuity in the outpatient setting. Given these

trends, they point out the need to address ethical issues in non-hospital settings: “[e]specially as our entire population ages, more and more care is given in long-term care facilities and through [hospice and] home health agencies. The result is a growing need to find ethics structures that transcend organizational boundaries and provide better continuity of services.”²²

A number of MCOs have also established ethics committees. While some MCOs, such as Kaiser Permanente and Harvard Pilgrim Health Care, have active committees and ethics programs, others devote little or no resources to HCECs. For example, in one study, none of the MCOs employing nurses to perform utilization review had an ethics committee to help nurse reviewers in the complex decisions they made regarding medical care utilization.²³ Guzman observed in the late 1990s that the focus of bioethics in managed care had shifted from case consultation to policy development and education and that ethics committees were influencing policy in “a small but growing number of MCOs.”²⁴

Functions of HCECs

While HCECs vary in their mission and operation, most have three basic functions: education, policy development, and case consultation.²⁵ In their educational role, HCECs provide information and resources to hospital staff about issues in ethical decision making. Such education is typically accomplished through conferences, seminars, grand rounds, educational materials, resource centers, and so on. Ethics committee networks have been established in a number of states to provide educational resources and programs to assist ethics committees in their educational mission. HCECs may also engage in policy formulation on ethical issues affecting patient care. Examples of policies crafted or revised by HCECs include those addressing Do Not Resuscitate (DNR) Orders, artificial nutrition and hydration, informed consent, surrogate decision making, guardianship, determination of competency, medically ineffective treatment, and advance directives. Case consultation involves the actual discussion of a case by an ethics committee in response to a request from a staff person, patient or their agent, guardian, or surrogate. Case consultation can take two forms: (1) retrospective review, in which those involved in a consult seek feedback on a difficult decision that was already made, or (2) concurrent or prospective review, in which ethics committee members are actively involved in the case as a decision is being made.

A fourth function carried out by some committees is “organizational ethics.” This involves looking at ethical issues that arise more broadly within the institution on a system-wide basis. In some institutions, separate committees advise the institution on clinical ethics and organizational ethics; in others, one committee performs both functions. Some argue the two (clinical and organizational ethics) have different, albeit overlapping,

goals and functions and thus should be kept separate.²⁶ Others think that, because most ethical conflicts in a given health care institution have roots at the systems-level, a more efficient approach is to have one committee respond both to individual consult requests as well as to the organizational problems underlying them.²⁷ Trinity Health, a Catholic health care organization, has developed what it refers to as a “next generation model of clinical ethics.” This model involves a shift from a primary focus on education, policy, and case consultation/review to “system change through quality management.”²⁸

Types of cases that come to HCECs

While there are no comprehensive empirical data on the types of cases or frequency with which cases come to ethics committees, accounts in the literature indicate various common characteristics of cases that are referred to HCECs. Most cases involve the termination or withholding of life-sustaining treatment. In one study of randomly selected internal medicine physicians in the United States, a little over half had requested an ethics consult – most commonly for ethical dilemmas related to end-of-life decision making, patient autonomy issues, and conflicts over patient care.²⁹ Often, the cases involved patients who lacked decision making capacity. In some of these cases, there was a question about whether the patient was capable of making an informed decision, and health care providers wanted to know if they could rely on the patient’s consent or needed to consult a surrogate. This is common when a patient declines a life-saving treatment recommended by the medical staff. In addition, there may be a dispute or question about whether a patient is chronically ill, terminally ill, and/or “imminently dying.” While most reports in the literature discuss cases involving elderly adults, cases involving young adults, children, or infants may also come to the committee. In cases involving end-of-life care, types of treatments that may be at issue include ventilatory support, artificial nutrition and hydration, antibiotic therapy, CPR, kidney dialysis, surgery, and chemotherapy. Cases coming to the committees, however, are not limited to termination of life-sustaining treatment. Other issues that may arise include appropriateness of treatment, confidentiality, surrogate decision making, resource allocation, cost containment, and issues related to managed care.³⁰

While some cases coming to committees may simply require clarification of issues or facilitation of communication between parties, others involve disputes between patients, families, and providers. Such disputes may occur between an incapacitated patient’s family members and the patient’s treating physician, or between family members of such patients. Disputes may also arise between health care providers, for example, between physicians, or between nurses and physicians, but these cases seem to surface less frequently.

Common types of disputes

Difference in belief over what the patient wanted or meant by certain statements

Disputes over what an incompetent patient would have wanted may result from undocumented conversations, or different inferences drawn from the patient's statements or behavior. In the case of *Mack v. Mack*,³¹ involving a dispute between the wife and father of a patient who had been in a persistent vegetative state for several years, the parties each related stories that they believed conveyed the patient's desires regarding life support in his current state. After visiting his elderly grandmother who was unable to feed herself and required assistance, the patient had stated that if he ever got to the point where he "could not do for himself" he did not want to live. His wife concluded from this statement and others that he would not want to be kept alive via feeding tubes.³² However, when the patient was a boy his mother died of a stroke. At the time of the stroke, the patient's father was told that there was a small chance that his mother could be kept alive with surgery but that in all likelihood she would be an "80% vegetable." The boy's father chose to have the surgery but his wife died before anything could be done. A few years later the boy thanked his father for considering the surgery. The father believed that this demonstrated his son's desire to be kept alive even with minimal quality of life.³³

Interpretation of terms

A patient's advance directive may include terms that are not well defined and may be interpreted differently. For example, a patient's living will may state that the patient does not want life-sustaining treatment if terminally ill with no hope of recovery.³⁴ What constitutes being "terminally ill" with "no hope of recovery" is open to interpretation. Physicians and family members may have differing opinions of a patient's medical prognosis and apply different definitions of "terminal illness." The law in most states does not clearly define terminal illness and leaves room for physician interpretation of the term. Some physicians may decide that someone is terminally ill if they have a life expectancy of six months or less; others may believe that someone is not terminally ill unless they can predict with a good deal of medical certainty that the patient will die within a few weeks. Physicians also have discretion in deciding what is meant by "no hope of recovery." Neither living will forms nor state statutes define the term.³⁵

Differing perceptions of the benefits and burdens of a proposed treatment and quality of life

Physicians and patients or their family members may disagree over the benefits and burdens of continued life support and quality of life issues.

Physicians may focus more on the probability of "success" of a certain procedure than on the patient's quality of life after the procedure. Family members, however, may see the burdens associated with life in a persistent vegetative state or with advanced Alzheimer's and not see the benefit of continued treatment. Alternatively, in some cases, family members may believe that life itself is sacred, no matter what its quality, whereas the physician may think that life in certain states is not worth sustaining.³⁶ Physicians and family members, for example, disagreed over the care of Helga Wanglie, an eighty-eight-year-old woman in a persistent vegetative state. Her physicians wanted to discontinue life support, arguing that it was futile to continue such support under those circumstances, while her husband felt her life was worth continuing.³⁷

Lack of clarity as to who has decision making authority

In some states, laws provide that a physician need not follow the instructions of a surrogate if to do so would be contrary to the physician's conscience or inconsistent with "generally accepted standards of patient care."³⁸ Such provisions, which may allow physicians to usurp decision making authority from family members, can also lead to disputes. The federal Baby Doe Rules,³⁹ in which decision making authority for the withholding or withdrawal of life support from newborns is given largely to physicians, have also led to disputes in cases where parents believe they should be allowed more input into these decisions.⁴⁰ Confusion over who can speak for a patient can also originate from lack of an available surrogate decision-maker or disagreement over who should serve as the surrogate. In the well publicized case of Terri Schiavo, a Florida woman in a persistent vegetative state, family members fought bitterly over who should speak for Terri and whether her feeding should be continued. Michael, her husband, requested that her tube feedings be stopped. Her parents challenged Michael's stewardship as surrogate decision-maker, based on allegations that he had financial and personal conflicts of interest.⁴¹

Disagreement over when treatment is futile

Different views about futility and the role of spiritual beliefs in effecting a "cure" create disagreements when decisions have to be made about withholding or withdrawing life-prolonging treatments. In the case of a 16-month-old with AIDS who was in constant, agonizing pain, the foster parents thought life support was not futile because God, not man, should make the decision as to when life ends, whereas the health care providers involved viewed the treatments as futile based on the inability to achieve a medical goal.⁴² In the oft cited case of Baby K,⁴³ the hospital sought a declaratory judgment that it had no duty to provide life-sustaining treatment for an

anencephalic infant over objections of the mother. The U.S. Court of Appeals for the Fourth Circuit held that under the federal Emergency Medical Treatment and Labor Act (EMTALA)⁴⁴ the hospital had a duty to treat Baby K. The Court determined that resuscitating Baby K (who would present in respiratory distress) and putting her back on a ventilator was not medically futile because her admitting diagnosis was respiratory failure, not anencephaly. However, according to a dissenting opinion in the case, there was no obligation to resuscitate Baby K under EMTALA because the relevant condition was anencephaly, not respiratory failure.⁴⁵

Cases arising in non-hospital settings

While most of the literature has focused on cases that come to hospital ethics committees, issues that arise in non-hospital settings may be quite different from those arising in acute care settings. For example, in long-term care facilities, committees may confront questions about the use of chemical or physical restraints, sexual relations between residents, and behavior management (issues that are referred to as matters of “everyday ethics”).⁴⁶ In home health care, ethical issues addressed by HCECs include maintaining agency solvency without denying care to patients who lack financial resources, practicing health care in situations where patients may be abused or neglected, inadequate care of a patient by the patient or family, termination of home care services (abandonment), and racial intolerance of patients, family members, and/or staff.⁴⁷ In mental health and psychiatric treatment settings ethical issues most often involve maintaining patient confidentiality, boundary violations, and special concerns related to resource allocation.⁴⁸

Ethical concerns arising in MCOs often stem from their dual purposes of reducing unnecessary expenditures while maintaining quality. This often creates questions about the need for hospitalization or referrals to specialists and policy issues about coverage of new procedures. Dombeck and Olsan describe several ethical concerns about managed care ranging from conflicts in the fiduciary relationship between physicians and their patients to “making limited health care resources available to some at the expense of others.”⁴⁹

How are these cases handled by ethics committees?

Because there are virtually no regulations governing ethics committees, their operations and procedures vary from committee to committee. As regards the process of ethics consultation, committees may adopt different structural and procedural models. In some institutions the full committee may conduct the consult; in others, it may fall on a small team or subcommittee or, in a growing number of institutions, on an individual consultant. The issue of which model is most appropriate or effective is still unresolved in

the field. Rubin and Zoloth, who advocate that the full committee engage in consultation, have lamented that "it is a significant problem that there has been no systematic empirical research or sustained philosophical debate to date about the relative effectiveness and desirability of the competing models of doing ethics consultation."⁵⁰

Perhaps more troubling is the lack of consensus regarding deliberative or procedural models for ethics committees addressing the cases that come to them. At least four procedural models are described in the literature: (1) the case conference model, in which the focus is on hearing from all parties and analyzing the advantages and disadvantages of various options without making a specific recommendation; (2) the consultation model, which takes its name from the traditional medical consultation model, in which the committee acts as a consultant or expert and is expected to recommend a specific course of action; (3) the quasi-judicial model in which the emphasis is placed on conflict resolution and due process; and (4) the mediation model in which the committee acts as a facilitator and assists the parties in reaching a consensus on the issue in dispute. In both the consultation and quasi-judicial models the committee makes a recommendation to the parties as to how to proceed.⁵¹

There remain significant differences among scholars and practitioners as to which of these four models is most appropriate and effective. While the American Society for Bioethics and Humanities (ASBH) has embraced a facilitation model, there are voices that reject the model as inconsistent with the normative role of bioethics. These latter advocates argue that

[c]linical ethics cannot be agnostic when it comes to making a recommendation. The cases that come for ethics consultation involve real patients and families and real health care professionals, and they involve situations in which a real decision will be made. Advice, not simply a facilitated exchange is what is being sought and what ought to be promised.⁵²

When ethics committee members deliberate among themselves and attempt to arrive at a recommendation, relevant legal and ethical norms typically inform the committee's recommendation. Bioethicists have espoused a number of theories to guide ethical case analysis, such as principle-based ethics, casuistry, consequentialism, deontology, feminist ethics, and narrative ethics. Principle-based case analysis, based on applying and weighing the principles of respect for autonomy, beneficence, non-maleficence, and justice, was the first to gain widespread recognition.⁵³ However, some have criticized a principled approach as lacking in methodological application and biased toward concerns of individual autonomy.⁵⁴ This has led to a continuing conversation in bioethics about how ethical principles and theory should inform deliberation of cases brought before ethics committees.⁵⁵

When considering the cultural diversity within the United States and abroad, some argue that moral issues, which are contextually (e.g., culturally) based, cannot be “resolved” by bioethicists applying cross-cultural moral norms or theories.⁵⁶ Yet, universal moral theory is not necessarily incompatible with contextually based case analysis. For example, in the more communitarian cultures, the practices of truth-telling and informed consent are approached differently than in the United States. This, however, does not preclude applying a principles-based approach – rather, the principles will be weighed differently in the context of a communitarian culture, where respecting autonomy might involve allowing an individual to defer decision making to the group, and balancing benefits and harms might entail prioritizing group harmony rather than individual rights.⁵⁷ Likewise, use of narrative ethics⁵⁸ in case consultation does not preclude application of other ethical theories. Indeed, Macklin argues that many norms are relative to the moralities of individual cultures, while recognizing that basic human rights exist that must be protected across cultures.⁵⁹ Beauchamp, claiming that no prevailing ethical theory has been shown to serve any useful purpose in bioethics, calls upon bioethicists to shift the focus toward universal norms (e.g., principles, rights, virtues) that can be applied across practice settings.⁶⁰

While ethical norms play a role in HCEC deliberations, these are also influenced by the characteristics of the U.S. health care system, including growing numbers of uninsured and under-insured persons, technology that shifts the site of treatment from hospitals to outpatient settings, and pressures to cut costs, including an increasing penetration of MCOs.⁶¹ Profit status and religious affiliation may also influence ethics committees’ processes and deliberations. Few have studied the influence of an HCEC’s profit-status, per se, on ethics committee functioning, although much has been written about the ethical conflicts of interest that may be created by profit seeking. Dugan describes several ways in which religiously based health care organizations (HCOs) differ from non-religious HCOs in their approach to ethical issues. The former, he observes, use a wider “radar screen” by which to capture ethical dilemmas or conflicts in the net of issues for ethical deliberation (e.g., contraceptive sterilization in Catholic hospitals, which must abide by the norms of the U.S. Conference of Catholic Bishops’ Ethical and Religious Directives for Catholic Health Care Services); spend greater time researching and reflecting on how interventions that may be grounded in laws and ethical principles are also consistent with the organization’s religious mission and core values; and take a different approach to the integration of the organization’s mission into clinical decision making (i.e., equipping staff with “the skills and tools to integrate religiously based core values into all aspects of their responsibilities”).⁶² Heller believes that whether or not an HCO’s religious affiliation makes a difference in the nature of the ethical issues it confronts or in the way its ethics committee and consultants work is case specific.⁶³

Legal evolution of ethics committees

As stated above, ethics committees have remained largely unregulated in the United States, yet court opinions and statutes in some states have encouraged their establishment, protected their members from liability, mandated basic requirements for membership and due process, and/or given them legal authority for health care decision making. While the majority of courts seem to have embraced the notion of ethics committees, not all have agreed with the wisdom of allowing them to substitute for judicial decision making. Shortly after the *Quinlan* case, the Massachusetts Supreme Judicial Court, in the case of Joseph Saikewicz, a sixty-seven-year-old, never competent, terminally ill cancer patient, challenged the assumptions of the *Quinlan* court regarding the merits of HCECs. The court stated that questions of life and death

require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower courts, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.⁶⁴

Other courts also expressed skepticism about granting decision making authority to HCECs, especially in the early stages of their development. One court described them as "ill-defined, amorphous bod[ies], which in some hospitals may not even exist."⁶⁵

However, there has been an equally vocal, if not louder, call by a number of courts for the establishment in health care institutions of bodies, such as ethics committees, to deal with the difficult end-of-life care cases that come to them. For example, in *In re Jobes*,⁶⁶ in which the husband of a non-elderly woman who was comatose and in a nursing home brought suit seeking termination of her life-sustaining nutrition and hydration, the N.J. Supreme Court stated that

courts are not the proper place to resolve the agonizing personal problems that underlie these cases. Our legal system cannot replace the more intimate struggle that must be borne by the patient, those caring for the patient, and those who are about the patient. The challenge for the courts will be to evolve innovative and flexible processes by which affected individuals can participate comfortably and confidently to secure the vindication of the interests we all seek to protect.⁶⁷

In a concurring opinion in that case, Justice Pollack more specifically mentioned the need for ethics committees stating that "[a]s an aid to physicians and families, hospitals and other health care facilities, such as nursing

homes, should give serious consideration to making available the services of ethicists and institutional ethics committees.”⁶⁸

In 1990, the Court of Appeals for the District of Columbia was called upon to determine “who has the right to decide the course of medical treatment for a patient who, although near death, is pregnant with a viable fetus” and “how that decision should be made if the patient cannot make it for herself.”⁶⁹ The judge, speaking for the court, stated in a footnote

We observe . . . that it would be far better if judges were not called to patients’ bedsides and required to make quick decisions on issues of life and death. Because judgment in such a case involves complex medical and ethical issues as well as the application of legal principles, we would urge the establishment – through legislation or otherwise – of another tribunal to make these decisions, with limited opportunity for judicial review.⁷⁰

More recently, in *Quill v. Vacco*, Judge Milner, writing for the Second Circuit, “suggested that a state might ‘require the establishment of local ethics committees as resources for physicians’ in order to deal with such difficult questions as physician assisted suicide.”⁷¹

State legislatures have also encouraged the establishment of HCECs but have done little to assure their quality. The Maryland law, enacted in 1987, is unique in providing requirements for committee membership and due process. The law, in addition to requiring all hospitals and nursing homes in the state to establish such committees, requires that the committees must have at least four members, including a physician, a nurse, a social worker, and a hospital’s chief executive officer or designee.⁷² Other members may be added as the hospital chooses, including representatives of the community and ethical advisors or clergy.⁷³ Each committee must set forth in writing how it shall be convened. It must make a good-faith effort to notify patients and their immediate family members of their rights to petition the committee for assistance. Each committee must also meet with these patients and their immediate family members concerning “options for medical treatment”; it must also provide the patient and immediate family members with an explanation of the “basis of the advisory committee’s advice.”⁷⁴ As part of its deliberations the committee must consult all members of the patient’s treatment team, the patient, and the patient’s family. The Act further provides that the proceedings of the committee are confidential and that the advice of the committee must become part of the patient’s medical record.⁷⁵

A few states have provided protection from liability for ethics committee members. The Maryland statute provides that committee members who give advice in good faith may not be held liable in court for the advice given.⁷⁶ In other states, including Arizona, Hawaii, and Montana, statutes grant immunity from civil or criminal liability “to members of ethics committees

or healthcare providers who rely on committee advice.”⁷⁷ As a result, as one author has noted, disputes considered by these committees “are increasingly unlikely to be reviewed substantively by a court.”⁷⁸ In a number of other states, existing statutes that protect peer review committees and medical staff committee proceedings may also protect members of ethics committees by preventing discovery of their meeting minutes and deliberations.⁷⁹

More recently, states have passed statutes allowing ethics committees to serve as “surrogate” decision-makers in cases where there is a dispute between family members or where no family members are available. In Maryland, if there is a dispute between surrogate decision-makers of equal standing regarding termination of life support for a patient lacking decision making capacity, the institutional ethics committee may make the decision. The patient’s physician may then act in accordance with the committee’s recommendation without fear of liability for any claim based on lack of consent.⁸⁰ In addition, the statute requires that where physicians believe a decision by surrogates or agents is “inconsistent with generally accepted standards of patient care,” they bring the case to the ethics committee or to court.⁸¹ Similarly, in Texas, ethics committees may serve as a dispute resolution body. When patients and physicians disagree about life-sustaining treatment, an ethics committee’s decision is final unless the patient is transferred.⁸²

In several other states ethics committees are given decision making authority when there is no legally authorized surrogate or when one is not available to speak with the patient. For example, the Arizona law regarding surrogate decision making states that if a health care provider cannot locate any of the surrogates designated by the statute in a case involving a patient who lacks decision making capacity, the “patient’s attending physician may make health care treatment decisions for the patient after the physician consults with and obtains the recommendations of an institutional ethics committee.”⁸³ The statute, however, further provides that “[i]f this is not possible, the physician may make these decisions after consulting with a second physician who concurs with the physician’s decision.”⁸⁴ The statute defines an “institutional ethics committee” as a “standing committee of a licensed health care institution appointed or elected to render advice concerning ethical issues involving medical treatment.”⁸⁵

In Alabama, the statute regarding termination of life support provides that if a patient

has no relatives known to the attending physician or to an administrator of the facility where the patient is being treated and none can be found after a reasonable inquiry, a committee composed of the patient’s primary treating physician and the ethics committee of the facility where the patient is undergoing treatment or receiving care⁸⁶

is authorized to make decisions “regarding the withholding of life-sustaining treatment or artificially provided nutrition and hydration.”⁸⁷ If there is no

ethics committee, a committee consisting of certain specified members and appointed by the chief medical staff or chief executive officer of the facility is authorized to make these decisions.⁸⁸ In either of these circumstances, the health care facility involved must notify the Alabama Department of Human Resources to allow the department "to participate in the review of the matter pursuant to its responsibilities under the Adult Protective Services Act."⁸⁹

In Florida, if a patient lacks an advance directive and is unable to make health care decisions for him or herself and the patient does not have a guardian or a family member or close friend who is authorized to make health care decisions for the patient, the bioethics committee of the facility in which the patient is located may select a clinical social worker who is either licensed or a graduate of a court-approved guardianship program to act as a surrogate for the patient.⁹⁰ If the social worker asks to withdraw or withhold life support, that decision must be reviewed by the facility's bioethics committee.⁹¹

In a few states, ethics committees are given the authority to review decisions to withhold or withdraw life-sustaining treatment when the patient is in a specific condition or when a specific type of intervention is going to be withheld. For example, Florida law provides that for patients in a persistent vegetative state, if the patient does not have an advance directive and there is no evidence of whether the patient would have wanted medical treatment in this state, life-sustaining treatment may only be withheld or withdrawn if a court-appointed guardian, in consultation with a medical ethics committee, concludes "that the condition is permanent and that there is no reasonable medical probability for recovery and that withholding or withdrawing life-prolonging procedures is in the best interest of the patient."⁹² In Georgia, if there is no legally authorized surrogate, an ethics committee, at the request of a physician with a concurring second opinion, may approve a DNR order for a patient.⁹³

In one state, a health care provider may be disciplined for failing to cooperate with an ethics committee. The North Carolina Medicine and Allied Occupations Article provides as grounds for the denial, suspension, or revocation of a license of a psychologist where the psychologist has failed to cooperate with or respond "promptly, completely, and honestly" to a hospital ethics committee.⁹⁴

Self-regulation

While these statutes have given ethics committees significant authority, they have imposed little or no requirements on committee composition, competency, or process. Although academic and certification programs in bioethics exist, there is currently no licensing of ethics consultants. Instead, ethicists rely on self-regulation by way of professional societies (such as the American Society for Bioethics and Humanities (ASBH) and the Canadian

Bioethics Society), or on the norms governing other professions to which they belong, such as nursing, medicine, or social work. The Canadian Bioethics Society convened an ad hoc working group on Employment Standards for Bioethics, which has been worked into a draft Model Code of Ethics for Bioethics.⁹⁵ However, the question of professional obligations of bioethics consultants and their scope of practice remains unresolved.

In 1998, the ASBH published its *Core Competencies For Health Care Ethics Consultation*.⁹⁶ The publication delineates which skills and sources of knowledge ethics committee members should possess, acknowledging that some members will have more ethical expertise than others, but that all should possess "minimum competencies." These are currently the only "industry wide" standards for ethics committees that have received some consensus in the United States.

Cases where ethics committees have been sued

In jurisdictions where ethics committees have not been granted immunity from liability as institutional committees giving advice to parties about patient treatment issues, they may be subject to lawsuit. While legal action against committees has been rare, it has occurred, most often in cases involving a dispute over whether continuing treatment is futile. Perhaps the earliest suit against an ethics committee was that brought by Elizabeth Bouvia in the mid 1980s.⁹⁷ The case involved a dispute between a competent patient and her physician, the hospital, and members of the hospital ethics committee who agreed with the physician's decision to feed the patient against her wishes through a nasogastric tube. By reasoning that the decision was not a medical one nor a "conditional right subject to approval by an ethics committee," a California Appeals court held that the feeding tube should be removed. Subsequently, Bouvia sued the hospital and the physicians for damages, and went so far as to name the ethics committee members in the complaint. Bouvia, however, decided not to pursue the suit against the committee members and subsequently dropped the suit against the hospital and physicians to avoid publicity.⁹⁸

Fletcher has described several other cases brought by patients or their family members against the chair or members of an HCEC after the committee or a committee member determined that life-sustaining treatment would be medically futile and the patient's physician withheld or withdrew such treatment without consulting the patient's family.⁹⁹ In *Gilgunn v. Massachusetts General Hospital*,¹⁰⁰ a patient's daughter sued the hospital and the chair of the ethics committee (called the Optimum Care Committee (OCC)) for violations of the daughter's rights as a surrogate. The chairman of the hospital's OCC endorsed a DNR order without consulting the daughter, despite her previous objection. The physician weaned the patient from the respirator and the patient died. At trial, the jury sided with the hospital and physicians.¹⁰¹ The case was appealed but subsequently

dismissed, presumably as a result of settlement. In *Estate of Bland v. Cigna Healthplan of Texas et al.*¹⁰² the patient's family brought suit for intentional infliction of emotional harm due to a decision made by the chair of the ethics committee to remove the patient from a respirator without consulting the family or the patient's original physician. The suit was settled out of court.¹⁰³

Similar cases were filed in Pennsylvania and Virginia. In *Rideout v. Hershey Medical Center*,¹⁰⁴ the parents of a two-year-old comatose patient who suffered from a brainstem tumor sued the hospital because the child had been removed from a ventilator against the parents' wishes. The hospital ethics committee agreed with the physician that a DNR order was appropriate and supported the decision to remove the child from the ventilator. A three-judge panel ruled that the parents could continue with their claims that the hospital committed assault and battery on the child, negligently and intentionally inflicted emotional distress on the parents, and impinged parental rights rooted in the free exercise of religion. However, the case was subsequently settled.¹⁰⁵ The 1996 Virginia case of *Bryan v. Stone, et al.: Bryan v. Rector and Visitors of the University of Virginia, et al.*, involved the family of a patient suffering from multiple disabling medical conditions. The family requested all possible treatment, including resuscitative efforts. Despite the protests of the patient's husband, the attending physician requested assistance from the ethics committee. After an ad hoc advisory committee convened by the ethics committee chair declared CPR to be futile, the physician wrote a DNR order and informed the patient's husband. The patient died eight days later. In their first law suit, the family sued the attending physician and members of the ad hoc group for violation of the patient's religious beliefs and some provisions of the Virginia Healthcare Decisions Act (VHDA).¹⁰⁶ The VHDA stipulates that physicians are not required to prescribe or render treatment that the physician determines to be "medically or ethically inappropriate," and that in such circumstances a good faith effort be made to transfer the patient to the care of another physician.¹⁰⁷ The suit was eventually dismissed.

More recently, suits against ethics consultants have been reported in the press. In response, the ASBH established a committee to make a recommendation on whether ethics consultants and members of ethics committees, not already covered under their institution's malpractice insurance policy, should obtain their own malpractice insurance coverage.¹⁰⁸

How have courts weighed recommendations by ethics committees in cases that have come to them?

A few courts have also been called upon to address disputes that were previously heard by an ethics committee. While these cases have also been relatively infrequent, in the cases that have been reviewed by the courts, the courts have been inconsistent in how they have regarded them. In a few

cases, they have ignored ethics committee recommendations. In others, they have treated the ethics committee recommendation as confirmation of a physician's determination. In at least one case, *In re Torres*,¹⁰⁹ the court noted that the record included the reports of three biomedical ethics committees that reviewed Torres' case, and appeared to regard the committees as authorities on moral issues.¹¹⁰

Courts may wish to give different weight to committee recommendations as ethics committees vary significantly in composition, experience, expertise, and procedures. Given the disparity among committees, in reviewing an ethics committee recommendation arguably courts should consider: (1) whether the ethics committee members have had any training in bioethics or law; (2) whether the committee includes community representatives or other individuals who can provide values that may differ from those of health care providers or other staff, for example, patients or family members of patients; and (3) whether the committee followed minimal elements of due process, including providing (i) notice and an opportunity for the relevant parties to be heard, (ii) evidence of diverse committee participation in the deliberative process, and (iii) a rationale for its final recommendation backed by relevant ethical and societal norms.

Conclusion

The role and legal status of ethics committees in the United States remains amorphous. Committees, for the most part, remain unregulated and disagreements exist in the field as to whether regulation is appropriate. Despite the lack of homogeneity in committee function and operation and the inconsistent quality in committee performance, a number of state legislatures have given HCECs legal authority to make health care decisions for patients lacking health care decision making capacity and/or available surrogates. While threats of malpractice may lead to improvements in ethics committee performance, in a number of jurisdictions ethics committees have been protected by statute from liability. In addition, suits have been rare and there are no published judicial opinions that have articulated standards for ethics committee process. As a result, committees continue to operate with minimum oversight and without legal standards.

Notes

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