

Successes and Failures of Hospital Ethics Committees: A National Survey of Ethics Committee Chairs

GLENN MCGEE, JOSHUA P. SPANOGLE, ARTHUR L. CAPLAN,
DINA PENNY, and DAVID A. ASCH

In 1992, the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) passed a mandate that all its approved hospitals put in place a means for addressing ethical concerns.¹ Although the particular process the hospital uses to address such concerns—ethics consultant, ethics forum, ethics committee—may vary, the hospital or healthcare ethics committee (HEC) is used most often. In a companion study to that reported here, we found that in 1998 over 90% of U.S. hospitals had ethics committees, compared to just 1% in 1983, and that many have some and a few have sweeping clinical powers in hospitals.²

Healthcare ethics committees formally began with the adoption of Committees for the Discussion of Morals in Medicine at U.S. Catholic hospitals in the 1960s. Healthcare ethics committees have three progenitors. In the 1960s, kidney-dialysis selection committees were established to introduce community representatives into the process of deciding which patients would receive kidney dialysis. In the 1970s, some states called for abortion review committees to determine which requests for therapeutic abortions were legitimate. In the 1980s, infant care review committees were established in some states to satisfy the federal mandate that intensive care nurseries be prevented from engaging in discriminatory practices against critically ill newborns. Drawing on these experiences, the 1976 New Jersey Supreme Court decision in the Quinlan case was interpreted by many as giving credence to the importance of such ethics committees for end-of-life cases, and the 1991 Patient Self-determination Act required that every healthcare organization in the United States receiving Medicare or Medicaid convene meetings of a committee to assure compliance with the requirements of that Act regarding advance healthcare directives. Under new requirements of the JCAHO, ethics committees

The authors acknowledge: John Fletcher and Jonathan Moreno of the University of Virginia; Diane Hoffman of the University of Maryland at College Park; and Charles Bosk, Sally Nunn, Jonathan Baron, and Paul Root Wolpe of the University of Pennsylvania for consultation and commentary during the development of this research program and the subsequent instrument and paper. Alex Capron (University of Southern California), Nancy Jecker (University of Washington), Daniel McGee (Baylor University), and Lois Snyder (American College of Physicians) served as an Advisory Board on Ethics Committee Research (ABECR) during years 1-3 of the research. This study was supported by a grant to the University of Pennsylvania Center for Bioethics from the Greenwall Foundation and by an unrestricted gift to the University of Pennsylvania Center for Bioethics from the American Association of Health Plans.

have dealt with the broad area of patients' rights, admission procedures, hospital policies regarding special interests of certain religious groups, the distribution of scarce healthcare resources, and other issues.

Yet the structure and function of ethics committees has not been systematically explored. Committees have been studied by ethnographers of particular clinical settings and by survey studies of inpatient hospital facilities in particular regions or states, but no national study has been conducted since 1983. The formation, structure, and focus of ethics committees are not federally regulated, and only Maryland mandates the existence of ethics committees; even Maryland does not specify their structure or focus.³ Nevertheless, there is some consensus in the literature about what functions the HEC should perform—education, consultation and mediation, policy formation^{4,5}—and much agreement about what issues the HEC should address—end of life, patients' rights, and staff and family conflicts.^{6,7,8} Accordingly, we performed a national survey of the self-reported successes, failures, and critical issues faced by U.S. ethics committees.

Methods

The target of this survey was a random sample of 1,000 hospitals, selected from all 6,291 hospitals in the United States as listed in the American Hospital Association's 1995 "census" of outpatient and inpatient hospitals. From January through October 1998, we mailed a self-administered instrument to each institution's director. A cover letter instructed the director to forward the instrument to the chairperson of the hospital's ethics committee. Target hospitals received up to two mailings. Each hospital was identified by a number written on the instrument.

Instrument

The instrument contained five sections that required structured responses, including descriptions of the hospital and the structure and function of its ethics committee. We then asked three open-answer questions:

- 1) What are the three functions or roles in which your committee is most successful?
- 2) What are the three functions or roles in which your committee is least successful?
- 3) What are the most pressing issues facing your ethics committee?
 - a. The most important clinical issues:
 - b. The most important procedural issues:

Content Analysis

Our analysis of the responses to open-ended queries proceeded through four stages. First, two investigators read all of the responses and identified and agreed on a list of distinct concepts expressed. These concepts were then divided into Functions (specific actions of the HEC) and Issues (matters of concern to the HEC). Six major functions were identified; some major functions allowed for further division. For example, the function "Education" was divided into five subcategories, including "Educating Patients," "Educating Physicians," and so on. Six major issues were identified.

Second, the returned questionnaires were ordered by identification number and divided into two groups. Every third returned questionnaire was incorporated into the training set, and the remaining two-thirds of the returned questionnaires were designated the test set. Each text response was assigned to a function category, an issue category, or both, depending on the nature

of the response. For example, a response like “[the most important clinical issue facing the HEC is] education of physicians about DNR” would be accorded a function code (Educating Physicians) and an issue code (End-of-Life). The responses in the training set were read, coded, and discussed by the two investigators in batches of 10–15 questionnaires at a time. Before proceeding to the test set, the two coders met to adjudicate differences, develop coding rules, and clarify the meaning of each code.

Third, the test set was coded independently by the two investigators. Interrater agreement was measured by kappa scoring. After testing for agreement, the two investigators adjudicated any differences on the test set. The final adjudicated results, both training and test sets, are presented here.

Results

Three hundred and fifty-six (356) instruments were returned to us by the cutoff date. Of these, five were left blank, 24 indicated no active HEC, and five indicated that the responding institution was not a hospital. Twenty-two HEC chairpersons did not respond to the section in the instrument rele-

vant to this paper but did respond to other parts of the questionnaire. Responses from the remaining 300 questionnaires were analyzed.

Kappa scores comparing coding for the two reviewers varied from 0.60 to 1.0, indicating excellent agreement.

Functions (Table 1)

Education

Education—broken into subcategories of general education; HEC self-education; and the education of patients, community, physicians, and hospital staff—was the most-cited function overall (Table 1). HEC chairs felt their committees were successful in most subcategories, including general education (135 most successful responses to 26 least successful) and HEC self-education (51 most successful to 15 least successful). Nationally, chairs did not feel HECs did well at educating the community (11 most successful responses and 39 least successful) or physicians (2 most successful and 14 least successful).

Mediation/Consultation

Three hundred and thirty-five (335) responses mentioned consultation, and

Table 1.

Function	Number of HEC chairpersons who felt			
	the HEC was most successful at: N (%)	the HEC was least successful at: N (%)	the most important clinical function was: N (%)	the most important procedural function was: N (%)
Education	247 (34%)	125 (31%)	9 (21%)	11 (8.9%)
Consultation/mediation	238 (33%)	58 (14%)	16 (37%)	23 (19%)
Policy work	162 (22%)	50 (12%)	3 (7.0%)	16 (13%)
Administrative concerns	19 (2.6%)	117 (29%)	7 (16%)	58 (47%)
Retrospective case review	25 (3.4%)	11 (2.7%)	3 (7.0%)	1 (0.81%)
Other	35 (5%)	40 (10%)	5 (12%)	14 (11%)

238 of those indicated that it was the most successful function of the committee. Fifty-six responses motivated the related theme of “providing a forum for discussion.”

Some chairs stressed the formal aspect of case consultation, most often when listing consultation as a least successful function. One chair noted that his or her committee was most successful at “using a model for case review” and least successful at “actual formal case consultation.”

Policy Work

Policy work was identified in 231 responses and largely fell into categories of “policy formulation” and “policy evaluation.” Of chairs who mentioned policy, most referred to policy in the most/least successful sections. Three HEC chairs felt that policy work was the most important clinical issue, and 16 felt that it was the most important procedural issue. When chairs specified their major policy activities, most mentioned policy relating to care at the end of life.

Administrative Activities

Some respondents noted the importance of logistics and general administrative problems. An HEC chair wrote that his or her committee had “too little time and human resources to remain an effective (consistently effective) committee,” whereas another noted the importance of “agreeing on standardized reporting mechanisms for formal consults.”

Frustration with physicians and hospital administrators is reported in the majority of these responses. In part the frustration stems from a reluctance of hospitals to utilize consultative services. One chair articulated most pointedly what proved a common sentiment; one of its committee’s least

successful functions was “getting resistant physicians to order/agree to formal consults.” Another said that the committee was least successful in getting “staff [to bring] cases to the committee—because they were afraid of physician retaliation.” This lack of support was reflected by a difficulty in generating interest to serve on that committee. A typical respondent wrote that two of its least successful functions were “sustaining outside member commitment and participation” and “physician membership.”

Concerns about resistant physicians were expressed in other ways. These complaints included “physician compliance with policies/procedures re: DNR orders, etc.” and “consultations with intimidating doctors unwilling to discuss alternatives with patient, family, or staff.” Lack of support for the HEC by administration was also frequently noted, including difficulty in “obtaining support/respect from senior administrative staff” and in “engaging leaders and administrative officials.”

Issues (Table 2)

End of Life

End-of-life issues fell into four categories, corresponding with kinds of cases in clinical settings rather than kinds of roles for the committee: advance directives/DNR, persistent vegetative state, futility, and general. The greatest number of responses fell into the general end-of-life category: 88 chairs felt it was the most important clinical issue and 26 felt it was the most important procedural issue facing their committee.

Forty-six respondents felt that DNR and advance directives were the most important clinical or procedural issues. A significant number identified what might be termed *compliance* issues: “getting physicians to document and honor

Table 2.

Issue	Number of HEC chairpersons who felt			
	the HEC was most successful at dealing with: N (%)	the HEC was least successful at dealing with: N (%)	the most important clinical issue was: N (%)	the most important procedural issue was: N (%)
End of life	30 (23%)	24 (22%)	149 (63%)	49 (43%)
Legal	11 (8.5%)	10 (9.1%)	10 (4.2%)	10 (8.7%)
Other clinical	31 (24%)	11 (10%)	31 (13%)	9 (7.8%)
Financial	0	36 (33%)	20 (8.4%)	11 (9.6%)
General/organizational ethics	46 (36%)	20 (18%)	8 (3.4%)	17 (15%)
Other	11 (8.5%)	9 (8.1%)	19 (8.0%)	19 (17%)

advance directives," "honoring DNR." Some mentioned policy issues such as implementing out-of-hospital DNR orders.

Thirty-one chairs held that futility was the most important clinical issue; two felt it was the most important procedural issue. For example, one HEC chair wrote that the most important clinical *and* procedural issue was "the 'futility' problem." Because futility is a term used many different ways in moral, legal, and clinical discourse, it is difficult to draw conclusions about what exactly the "futility problem" means, but a common thread among these responses is that of resource allocation at the end of life.

Administrative, Regulatory, and Legal Issues

This category covered three themes: risk management, competency of patients, and satisfying the JCAHO standard that some means be in place to address ethical concerns.

Only eight chairs listed risk management as either a most or least successful issue (two most successful, six least successful). One wrote that the ethics committee functioned "mostly for risk management" but was recently recon-

stituted and is "establishing policy/procedure/education." Another noted that the committee was least successful at "offering alternatives to risk management." A few responses mentioned JCAHO standards.

Twenty chairs wrote that Administrative, Regulatory, and Legal Issues were the most important clinical or procedural issues. Major themes included patient competency, patient surrogacy, and provider competency.

Non-End-of-Life Clinical Issues

This category comprised four issues: pain management, patients' rights, mental health/psychiatric issues, other treatment issues. Of these, "patients' rights" was the most frequently cited both clinically and procedurally, overlapping in obvious ways with several other categories. Twenty-five of 31 committees felt their committees were successful at dealing with patients' rights.

Financial Issues

Financial issues, encompassing themes of managed care, rationing, and cost containment, had the greatest number of "least successful" responses of any issue ($N = 36$). No respondent felt that

it was one of his or her committee's most successfully addressed issues.

Nineteen chairs felt that managed care, specifically, was the most important clinical or procedural issue. Frustration with managed care emerged as a dominant theme. One noted the "dilemma of providing the highest quality of care uniformly in a managed care environment."

General Ethics/Organizational Ethics

This category encompassed responses where the ethical issues were nonspecific; many respondents noted that they were successful at teaching "ethics." For example, one chair described the HEC as most successful at "awareness of ethical issues throughout the organization" and another wrote that the HEC was most successful at "keeping abreast of medical/ethical concerns."

Some referred to committee role and identity. They wrote that the most important procedural issue was "committee direction and goals" and "how invasive/directive to be with consultations." Three felt that their HECs were successful defining their role and identity. Eight committees felt that the "Role of the HEC" was the most important clinical or procedural issue. Self-examination among ethics committees had been suggested in previous studies but, more importantly, was cited as among the most important roles of the ethics committee in its institution.⁹

Other

Issues of genetic testing, culture and religion, abortion, fertility treatments, and compromised infants were mentioned only an average of three times each. Organ transplantation, however, was deemed a most important clinical or procedural issue by five chairs. Two felt successful with transplantation questions, yet all five thought that

the committee was at least partially unsuccessful—one wrote that the committee was least successful at "changing beliefs re: donation" and another at "mak[ing] referrals for organ donation with slow family acceptance."

Discussion

The goals of this study were to learn how hospital ethics committees perceive their roles, successes, and failures. Despite wide variation in responses to the questions, certain patterns emerge. We draw several conclusions from the findings presented.

First, HEC chairs saw their committees as active in four major areas: Education, Consultation/Mediation, Policy Work, and Administrative Activities. Of these, Education, Consultation/Mediation, and Policy Work are traditionally thought of as normal roles for the HEC.^{10,11,12} If HEC chairs did not always feel successful in these roles, at least they felt successful more often than not. We do not know whether clinicians and patients value those efforts of ethics committees, or whether those efforts affect clinical outcomes.

Second, ethics committees were concerned in the main with end-of-life issues. Indeed, we found that a common language concerning end-of-life issues has been adopted by most chairs. Whereas the investigators had to decide among many possible interpretations for other functions and issues, the phrases and words describing end of life were familiar, clear, and recurrent: "end-of-life," "DNR," "withholding/withdrawing care," and "futility."

Third, committees felt that administrative issues were among the most important facing them and that they are unsuccessful with those issues. The reason for the importance of administrative issues may lie in the fact that these issues precede all others. Before an HEC can consult, or mediate, or

educate, the committee must have interested members, space in which to meet, and cases for which to consult. Only a few identified that the committee did well at addressing its place in the institution.

Fourth, the comments presented here suggest that committee relationship with clinicians is complex. For example, although many chairs felt their committees excelled at education, this success did not apply to educating clinicians. Some of the most negative responses were reserved for physician arrogance or disrespect of the committee. This is especially interesting considering that physicians enjoy the greatest representation on HECs.¹³

Fifth, many HEC chairs felt that issues pertaining to money, managed care, and rationing were important committee priorities. Twenty felt financial issues were the most important clinical issue facing the committee; 11 felt it was the most important procedural issue. Some HECs see themselves (or are seen by hospital organizations) as having a role in procedural or organizational issues that extends beyond the clinic.^{14,15}

The results presented here are subject to many limitations. First, the response rate to the survey was only 36%. In light of the difficulty in getting physician responses to written surveys,^{16,17} those who did respond to this survey may have been disproportionately nonphysicians. Second, we surveyed the chair of each HEC, whose opinions may not reflect those of the whole committee or those that independent observers might draw.

This study also has strengths. It is natural in scope and allowed HEC chairs to self-identify the roles, strengths, and weaknesses of their committees. Many HECs were created to meet externally imposed standards. But if HECs are to be useful, they will need help overcoming their difficulties.

Notes

1. JCAHO Standard RI. 1 .1. 6 .1. In: Comprehensive accreditation manual for hospitals. Oakbrook Terrace, Ill.: Joint Commission on the Accreditation of Healthcare Organizations, 1992:104.
2. McGee G, Spanogle JP, Caplan AL, Asch DA. A national study of ethics committees. *The American Journal of Bioethics* 2002;1(4): 74–80.
3. Hoffman DE. Does legislating hospital ethics committees make a difference? a study of hospital ethics committees in Maryland, the District of Columbia, and Virginia. *Law, Medicine, and Health Care* 1991;19(1–2):105–19.
4. Fletcher JC, Siegler M. What are the goals of ethics consultation? a consensus statement. *The Journal of Clinical Ethics* 1996;7(2):122–6.
5. Lynn J. Roles and functions of institutional ethics committees: the President's Commission view. In: Cranford RE, Doudera AE, eds. *Institutional Ethics Committees and Health Care Decision Making*. : Health Administration Press, 1984:85–95.
6. See note 4, Fletcher, Siegler 1996.
7. Fox E, Arnold RM. Evaluating outcomes in ethics consultation research. *The Journal of Clinical Ethics* 1996;7(2):127–38.
8. Hern HG. Ethics and human values survey: a study of physician attitudes and perceptions of a hospital ethics committee. *HEC Forum* 1990;2:105–25.
9. Moreno J. *Deciding Together: Bioethics and Moral Consensus*. New York: Oxford University Press, 1995.
10. See note 4, Fletcher, Siegler 1996.
11. Mahowald MB. Hospital ethics committees: diverse and problematic. *HEC Forum* 1989; 1:237–46.
12. See note 5, Lynn 1984.
13. Csikai EL. The status of hospital ethics committees in Pennsylvania. *Cambridge Quarterly of Healthcare Ethics* 1998;7:104–7.
14. Agich GJ, Youngner SJ. For experts only? access to hospital ethics committees. *Hastings Center Report* 1991;21(5):17–24.
15. Hoffman DE. Evaluating ethics committees: a view from the outside. *The Milbank Quarterly* 1993;71(4):677–701.
16. Asch DA, Christakis NA, Ubel PA. Conducting physician mail surveys on a limited budget: a randomized trial comparing \$2 bill versus \$5 bill incentives. *Medical Care* 1998;36(1):95–9.
17. Asch DA, Jedrzewski MK, Christakis NA. Response rates to mail surveys published in medical journals. *Journal of Clinical Epidemiology* 1997;50(10):1129–36.