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Developing Clinical Ethics Consultation and Committees

Structure, Operation, and Experience of Clinical Ethics Consultation 2007-2013: A Report from the Massachusetts General Hospital Optimum Care Committee

*Ellen M. Robinson, Wendy Cadge, Kimberly Erler,
Sharon Brackett, Julia Bandini, Alexandra Cist,
M. Cornelia Cremens, Eric L. Krakauer,
and Andrew M. Courtwright*

ABSTRACT

We describe the structure, operation, and experience of the Massachusetts General Hospital ethics committee, formally called the Edwin H. Cassem Optimum Care Committee, from January 2007 through December 2013. Founded in 1974 as one of the nation's first hospital ethics committees, this committee has pri-

marily focused on the optimum use of life-sustaining treatments. We outline specific sociodemographic and clinical characteristics of consult patients during this period, demographic differences between the adult inpatient population and patients for whom the ethics committee was consulted, and salient features of the consults themselves. We include three case studies that illustrate important consult themes during this period. Our findings expand

Ellen M. Robinson, RN, PhD, is Co-Chair of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; is a Nurse Scientist at the Yvonne L. Munn Center for Nursing Research at Massachusetts General Hospital; and is a Nurse Ethicist at the Institute for Patient Care at Massachusetts General Hospital in Boston, Massachusetts. erobinson1@partners.org

Wendy Cadge, PhD, is Professor in the Department of Sociology at Brandeis University in Waltham, Massachusetts.

Kimberly Erler, MS, OTR/L, is a Member of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is an Advanced Clinician in the Department of Occupational Therapy at Massachusetts General Hospital.

Sharon Brackett, RN, BS, CCRN, is a Member of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is a Clinical Scholar and Attending Registered Nurse in the Ellison 4 Surgical Intensive Care Unit at Massachusetts General Hospital.

Julia Bandini, MA, is a PhD Candidate in Medical Sociology at Brandeis University.

Alexandra Cist, MD, is a Member of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is a Physician at Massachusetts General Hospital.

M. Cornelia Cremens, MD, is Co-Chair of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is a Practicing Geriatric Psychiatrist in the Departments of Psychiatry and Internal Medicine at Massachusetts General Hospital.

Eric L. Krakauer, MD, PhD, is a Member of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is a Physician in Palliative Care at Massachusetts General Hospital and the Departments of Medicine and of Global Health and Social Medicine at Harvard Medical School in Boston.

Andrew M. Courtwright, MD, PhD, is a Member of the Edwin H. Cassem Optimum Care Committee at Massachusetts General Hospital; and is an Assistant Professor in the Division of Pulmonary and Critical Care Medicine, Hospital of the University of Pennsylvania in Philadelphia.

knowledge about the structure and workings of hospital ethics committees and illustrate how one ethics committee has developed and utilized policies on end-of-life care. More generally, we model a sociological approach to the study of clinical ethics consultation that could be utilized to contextualize institutional practices over time.

INTRODUCTION

A growing body of research explores the work of hospital ethics committees with attention to how they are composed, what they do, and how they influence the ethical delivery of healthcare. The majority of these studies focus on a single institution and explore a single aspect of an ethics committee such as the consultation process, the consulting service, or the ethical issues identified in the consults. Few systematic studies focus on all of these issues in a single institution or include data that span more than a single year.¹ We expand this literature by offering a holistic picture of how the Massachusetts General Hospital (MGH) ethics committee, formally called the Edwin H. Cassem Optimum Care Committee, did its work between 2007 and 2013. This committee was founded in 1974 and was one of the nation's first hospital ethics committees. It has focused primarily on the optimum use of life-sustaining treatments and has worked at both the clinical and administrative levels of the hospital to draft specific policies to guide decision making about life-sustaining treatment.

We begin by describing the general demographic differences between the hospital's inpatient population and the patients for whom the ethics committee was consulted during the study period. We then discuss more specific demographic and clinical characteristics of the consult patients. We consider who requested the consult, why it was requested, what service the ethics consultants provided, and the patient's outcome. We include a detailed description of three cases that are representative of important thematic consultation categories. Our findings expand knowledge about hospital ethics committees, and we model a sociological approach to the study of ethics consultation that can be used comparatively across healthcare institutions and over time.

BACKGROUND

The number of hospitals with ethics committees has risen significantly in the past 40 years and corresponds with several national events and legislation, including the 1976 *Quinlan* case,² the 1983 President's Commission report, *Deciding to Forego*

Life Sustaining Treatment,³ the 1984 Baby Doe Law,⁴ the 1990 Patient Self-Determination Act,⁵ and the 1992 Joint Commission on Accreditation of Healthcare Organization requirements that hospitals have a mechanism to address ethical issues that arise in patient care.⁶ Today, all United States hospitals with more than 400 beds have an ethics committee, although the process by which these committees do their work and how their recommendations are received vary significantly across institutions.⁷ This growth has been accompanied by an ongoing discussion about the optimum size, training, and composition of these committees, with particular attention to best practices and evolving professional standards.⁸

A growing body of empirical literature, focused primarily on single-center experience, describes the consultation work of hospital ethics committees.⁹ Some of these studies assessed the prevalence and predictors of consults, and found that most consultations take place in the intensive care unit (ICU).¹⁰ Others investigate which medical professionals request consults, what substantive issues are identified, and how consults influence patient care and decision making.¹¹ Some studies also consider the quality of care or the financial aspects of the consult process.¹² Few studies, however, look at all of these issues together or include large numbers of cases over time.

One of the central questions in studies of ethics committee consultation is how often consults focus on conflict about the use or non-use of life-sustaining treatments and/or issues of medical futility.¹³ A review of 10 years of ethics consultations at the Mayo Clinic reported that 82 percent of consults involved patients' competency and decision-making capacity, 76 percent involved staff members' disagreement with care plans, 60 percent involved end-of-life and quality-of-life issues, 54 percent related to goals of care and futility, and 52 percent included issues around withholding or withdrawing life support.¹⁴ In their study of seven hospitals in the New York-Presbyterian Healthcare System, Nilson and colleagues found that a majority of ethics consults involved conflicts over care related to life-sustaining treatments.¹⁵ These conflicts were between staff and family as well as within staff and within families.

A central, although not exclusive, focus of our ethics committee is to provide recommendations about optimum use of life-sustaining treatment. Any health professional, patient, family member, or surrogate decision maker can request consultation. In addition to questions about the appropriate use of life-sustaining treatments, our committee also ad-

dresses issues related to the interpretation of advance care planning documents, decision-making capacity, decision making for patients without surrogates, extracorporeal membrane oxygenation, optimum discharge planning, and palliative sedation.

In most cases, two or three ethics committee members, led by a senior consultant, respond to requests for consultation. The consultants are trained using a mix of self-learning strategies. New committee members who are interested in consultation are expected to do the following:

1. Review a collection of relevant bioethical and legal articles outlined in a text published by the American Society for Bioethics and Humanities (ASBH), *Improving Competencies in Clinical Ethics Consultation: An Education Guide*;¹⁶
2. Participate in seminar-based learning, involving one or more single-day classroom courses jointly sponsored by multiple ethics committees across the city; and
3. Participate in experiential learning, accompanying senior members on ethics consultation in an observational role, learning the process of ethics consultation, relevant hospital policies and professional society guidelines, and writing consultation notes.

The goal of this education is for all active committee members—and certainly all senior consultants—to have developed the core competencies outlined by the ASBH.¹⁷

Through the process of ethics consultation, our consultants aim to honor each patient's dignity and values, mitigate conflict, balance ethical principles, and provide emotional support for patients, loved ones, and the healthcare team by placing the values and experience of patients at the center of its deliberation. When called, consultants review the patient's medical record and speak to involved parties to understand the ethical issue; the patient's prognosis; and the patient's values, wishes, and treatment preferences. The consultants then conduct an ethical analysis of the consult question and make recommendations that are entered into the patient's medical record. These analyses and recommendations are not based on specific, pre-existing categories, but reflect the details of each individual case. They take the form of semi-structured narrative notes that are also provided, in de-identified form, to the full committee (see figure 1). Consultants may also attend a team or team-family meeting, depending on the situation, and occasionally consult with the team alone, as long as that does not inappropriately exclude the perspectives of the patient or surrogate.


A small rotating group of committee members provides consultations, and the full committee meets monthly for a retrospective review of consult activity. This process serves as a peer review, hospital policy review, and quality improvement mechanism, allowing the full committee to reflect on the approach taken in specific consultation cases, trends in consultation questions, and areas where relevant hospital policy might be developed or expanded. The committee has become more professionally diverse over time and now has representation from more than 10 separate professions, in addition to community members.¹⁸

The number of consult cases has increased from less than 10 per year in the 1970s, to 40 per year by the late 1980s, to well over 100 per year today. While a systematic historical study of the committee has not been completed, Edwin H. Cassem, SJ, MD, described key themes at an Institute of Medicine workshop in 1993.¹⁹ Looking back over the first 15 years of consults, Cassem said the most common cases involved pre-existing conflicts within families of incompetent patients that manifested as disagreement over the appropriate use of life-sustaining treatment, situations in which families or surrogates were asked to decide about end-of-life care without clear medical guidance, and treatments that healthcare professionals felt were futile but for which clear legal precedent for withholding or withdrawing was lacking. Additional themes included physicians' uncertainty about end-of-life care, questions about stopping artificial hydration and nutrition, clinical judgment of prognosis, and care for patients who were in a persistent or permanent vegetative state. Brennan described a subset of MGH ethics committee consults in a 1988 article focused on care for terminally ill patients, but little else has been written about the committee's historical work.²⁰

METHODS

We triangulated several sources of data to describe the ethics committee's consult work between 2007 and 2013. First, to better understand the characteristics of patients for whom ethics consultation was requested, we compared demographics of the ethics consultation population to that of the broader inpatient population. We did this by collecting sociodemographic information on all adult MGH admissions between 1 January 2007 and 31 December 2013, using the MGH Research Patient Data Registry (RPDR).²¹ Data included age, race/ethnicity, primary language, insurance status, and median household income by zip code, as described previ-

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 **MASSACHUSETTS
GENERAL HOSPITAL**

EDWIN H. CASSEM, M.D. OPTIMUM CARE COMMITTEE CONSULTATION

Patient's Name:	
MRN:	
Date of Admission:	
Unit / Location:	
Date of Consultation:	
Consultation Requested By:	
Treatment Team (include responsible attending physician):	
OCC / Ethics Consultants:	
Persons With Whom Consultants Spoke:	

Issue(s), question(s) or problem(s) prompting consultation:

Medical History *(include a description of the patient and/or relevant physical examination and diagnostic test results, type and content of any advance directive, and prognosis if relevant):*

Family/Social History:

Major Viewpoints Among Stakeholders:

Ethical Analysis *(include relevant ethical issues, laws, hospital policies, or case precedents):*

Summary & Recommendations:

- ▶
- ▶
- ▶

Ethics Consultant(s)	Phone Number	Beeper Number

FIGURE 1. Template for ethics consultation documentation. This note was revised from earlier version developed by the Brigham and Women's Hospital ethics committee.

ously.²² To compare general inpatients with ethics consult patients, we focused on age (<65 versus >65), race/ethnicity (White versus non-White, including Hispanic), primary language (English versus non-English), insurance status (insured versus underinsured), and median household income (nonlow income versus low income, defined as median household income in the bottom two quintiles of the U.S. median household income). Each was treated as a categorical variable. Cases with missing or incomplete data were excluded. *Chi-squared* tests were used to compare each variable between general inpatients and ethics consult patients. We constructed a logistic regression model to examine the adjusted association between all variables with a *p*-value = 0.05 in bivariate analysis and ethics consultation.

Second, to quantify specific clinical characteristics of patients for whom the committee was consulted and to characterize the consultations themselves, we created an Ethics Consultation Database. Drawing on the experience of senior members of the committee, all of whom had more than 20 years of work in ethics consultation, we used an inductive analytic process to identify basic demographic, clinical, and consultation characteristics of interest. Once preliminary consensus was achieved, data categories were further revised with a focus on statistical power and the ability of the database to answer our *a priori* research questions, including the comparative analysis described above and projects investigating the use and outcomes of policies on limitation of life-sustaining treatment. Two broad categories—reason for consultation as identified by requestor and ethics service provided—were further revised, using iterative sampling, whereby the preliminary consensus categories were reviewed after testing against a random sampling of cases. Collectively, the development of the Ethics Consultation Database required multiple meetings during which this interdisciplinary team identified, critiqued, revised, discarded, and finally agreed upon categories that represented the consultation process at our institution.

Following completion of the Ethics Consultation Database categories, we reviewed all of the consultations, regardless of whether the consult question was about optimum use of life-sustaining treatment or another topic, from the beginning of 2007 to the end of 2013. We obtained detailed sociodemographic and clinical data from medical records, as previously described.²³ In addition to the categories noted for the comparative analysis, this included birthplace, educational attainment, major co-morbidities on admission, functional status prior to admission, de-

cision-making capacity, number of life-sustaining treatments, and severity of illness at the time of consultation.²⁴ Finally, we reviewed separate records of the ethics consultations. These records consisted of narrative reports that ethics consultants write and file after each case. They include salient medical and psycho-social-spiritual details about the case, information about the requestor and the reason for consultation, names of stakeholders with whom the consultants spoke, the primary ethical issues as interpreted by the consultants, and the consultants' recommendations.

We excluded cases in which the consultation was referred to another service and was not seen or followed by ethics consultants or when patients died before an initial consultation. When the committee was consulted more than once for the same patient, we categorized the ethics service that had been provided according to the final consult recommendations. One author (ER) abstracted and coded all of the information about each consultation (Pearson's correlation coefficient for intraobserver variability = 0.95). A second author (AC) confirmed the type of ethics services provided, patients' sociodemographics, and final disposition. The study data were collected and managed using Research Electronic Data Capture, an electronic data capture tool hosted at MGH.²⁵ Quantitative data were analyzed using Stata, Version 14.

Finally, to illustrate common types of ethics committee activities, we summarized case studies from among those reviewed that best demonstrated common themes in our ethics consultation service. The MGH Institutional Review Board approved all three aspects of data collection and analysis utilized in this study.

RESULTS

Differences with the General Inpatient Population

Between 1 January 2007 and 31 December 2013, we identified 286,662 inpatient adult admissions in RPDR; of these, 42,075 (14.7 percent) were excluded due to incomplete information. During this same period, there were 314 unique ethics committee consultations. Four cases (1.3 percent) were excluded because they were referred to another service, and two cases were excluded from the comparative analysis due to incomplete information (0.6 percent). Of these 314 consults, 19 patients (6.1 percent) had two or more separate consultation requests, and six (1.9 percent) had three or more.

As compared with the general inpatient population, patients with ethics consultation were more

likely to be older than 65, to be non-White, and to have a non-English primary language in bivariate analysis (see table 1). They were also more often to have a lower income and to be underinsured. In multivariate analysis, patients older than 65 and non-White patients remained disproportionately represented in ethics committee consultation, when compared with general adult inpatients (see table 2). Underinsured patients were also disproportionately represented.

Demographic and Clinical Characteristics of Consult Patients

The demographics of the 310 patients seen by ethics committee consultants between 2007 and 2013 are described in table 3. On average, patients were 65 years old and were slightly more often male (57.7 percent). The majority were White (70.3 percent) and spoke English as their primary language (85.2 percent). Slightly more than one-quarter (26.5 percent) were born outside of the U.S. Their median household income was \$69,918, and 17.9 percent were in low income households. Slightly more than three-quarters of the patients were insured (77.4 percent) and among those for whom educational status was known, slightly more than half had a high school diploma or less than a high school education. Close to one-third (31.9 percent) were completely independent before they were admitted. Most (55.2 percent) were admitted from home, although a significant number came from a skilled nursing, assisted living, or rehabilitation facility (23.9 percent) or from another hospital (18.1 percent).

Consultation patients had a median of three comorbidities on admission (see table 4). At the time of consultation, patients were receiving a median of two life-sustaining treatments, and the majority had been hospitalized for less than three weeks (20 days on average). Almost 90 percent were identified as seriously or critically ill. Almost three-quarters (74.2 percent) did not have a do-not-resuscitate (DNR) order. They varied in their alertness and decision-making capacity; most were not alert (41.9 percent) or were alert but without decisional capacity (23.5 percent). Slightly more than half (51.9 percent) had a formal healthcare proxy document. More than half of the patients died in the hospital (51.6 percent); 34.2 percent were discharged to a skilled nursing or long-term acute care or rehabilitation facility; and 14.2 percent were discharged to their home.

Characteristics of Ethics Consults

House staff, nurse practitioners, and attending physicians requested the majority of consultations

(68.4 percent) (see table 5). Fewer consultations were requested by a staff nurse (14.8 percent), a clinical nurse specialist or nurse director (9.4 percent), or a social worker (2.9 percent). Almost no consults were requested by family members or surrogate decision makers. Internal medicine, including oncology, was the most common consulting service (in 56.6 percent of cases). Surgery (17.4 percent) and neurology or neurosurgery (15.8 percent) were also common, with fewer consults requested by anesthesia (3.9 percent), palliative care (3.2 percent), or other services (3.2 percent). More than half of the patients (52.5 percent) were in an ICU when the consult was requested.

The three most common reasons for requesting a consultation were moral support or confirmation of the appropriateness of actions (41.9 percent), a surrogate decision maker who requested more interventions than health professionals believed were

TABLE 1. Bivariate comparison between adult inpatients and all ethics consultation patients, 2007-2013

Variable	Inpatients (n = 244,587)		Ethics consultations (n = 308)*		p-value
	No.	%	No.	%	
Age >65	9,6472	39.4	162	52.6	<.0001
Non-White race	4,5255	18.5	92	29.9	<.0001
Non-English primary language	2,1850	8.9	45	14.6	0.001
Low income	1,1639	4.8	25	8.1	0.008
Underinsured	3,8102	15.6	69	22.4	0.001

*2 cases were excluded because of incomplete information on income status.

TABLE 2. Multivariate comparison between adult inpatients and all ethics consultation patients, 2007-2013

Variable	OR	95% CI	p-value
Age >65	2.05	1.62-2.59	<.0001
Non-White race	1.97	1.47-2.64	<.0001
Non-English primary language	1.04	0.72- 1.51	0.82
Low income	1.50	0.99-2.27	0.06
Underinsured	1.40	1.04- 1.88	0.03

OR = odds ratio; CI = confidence interval

appropriate (41.3 percent), and the need for clarification of the patient's values and preferences (32.3 percent). Other common themes included assistance in identifying a surrogate (23.2 percent) and assis-

tance in interpreting or applying a hospital policy or state statute (20.0 percent). One such policy provides guidance on not offering cardiopulmonary resuscitation (CPR) to patients who are imminently dying, if attempting CPR is deemed to be more harmful than beneficial in the context of the patient's values and clinical condition. One such statute is a Massachusetts law concerning healthcare proxies that reserves the right to provide "comfort care or pain alleviation" to the attending physician.²⁶ Less common reasons for consults were disagreement among family members or potential surrogates (11.3 percent), assistance interpreting advanced care planning documents (10.6 percent), disagreement among clinicians (9 percent), the team's desire to provide more care than a patient or surrogate (7.7 percent), a patient's desire to receive more care than the team would provide (5.8 percent), and questions about resource allocation (2.6 percent).

TABLE 3. Demographics of patients for whom the ethics committee was consulted, 2007-2013 (N = 310)

Variable	Consultations	
	n	%
Age in years: 64.7±19.5		
Female sex	131	42.3
Race		
White	218	70.3
Black	40	12.9
Asian	22	7.1
Hispanic	20	6.5
Other	10	3.2
Primary language		
English	264	85.2
Spanish	11	3.5
Cantonese or Mandarin	9	2.9
Other	26	8.4
Born outside the U.S.		
Yes	82	26.5
Unknown	14	4.5
Median household income by ZCTA: \$69,918±\$26,791*		
Median household income in bottom 2 quintiles of U.S. median household income*	55	17.9
Insurance status		
Insured	240	77.4
Underinsured	70	22.6
Education level		
No high school diploma	31	10.0
High school diploma	135	43.5
College graduate or postgraduate school	78	25.2
Unknown	66	21.3
Functional status prior to admission		
Complete independence	99	31.9
Partial dependence	146	47.1
Complete dependence	65	21.0
Residence prior to admission		
Home	171	55.2
Skilled nursing, assisted living, or rehabilitation facility	74	23.9
Hospital transfer	56	18.1
Other	9	2.9

* Excludes 2 patients with unknown ZIP Code tabulation area (ZTCA)

TABLE 4. Clinical characteristics of patients for whom the ethics committee was consulted, 2007-2013

Variable	Consultations	
	No.	%
Major co-morbidities on admission: median: 3; IQR: 2-4		
Hospitalized in intensive care unit	164	52.5
Number of life sustaining treatments: median: 2; IQR: 1-3		
Severity of illness		
Good	5	1.6
Fair	30	9.7
Serious	137	44.2
Critical	138	44.5
Full code status	230	74.2
Alertness and decision-making capacity		
Alert with full capacity	52	16.8
Alert with fluctuating capacity	55	17.7
Alert with no capacity	73	23.5
Not alert with no capacity	130	41.9
Advance care planning documents		
Formal health care proxy document	161	51.9
Advance directive	9	2.9
Final disposition		
Death	160	51.6
Skilled nursing, long-term acute care, or rehabilitation facility	106	34.2
Home	44	14.2

IQR = interquartile range

The ethics consultants provided a range of services. Most frequently, the consultants commented on the ethical appropriateness of plans or actions (67.4 percent). They also identified conflict between clinicians and surrogates (42.3 percent) and worked to improve the surrogate and team relationship (32.6 percent). Other services included interpreting or applying hospital policies (28.7 percent), clarifying patients' values and preferences (27.4 percent), and identifying appropriate surrogates (21.6 percent). The other hospital resources most commonly suggested by consultants were palliative care, the Office of the General Counsel, and chaplaincy. In 35.5 percent of cases, ethics consultants met with patients, families, and/or medical teams two or more

times. In 5.8 percent of cases, they had more than four meetings.

Case Studies

To describe ethics consultation at MGH, we include three case studies that focus on common themes of consultation. We describe how consultants identified ethical issues, their recommendations, and patients' outcomes following consultation. Details were changed to protect the confidentiality of patients and family members.

Disagreement between the surrogate decision maker and the healthcare team about the goals of care. Many ethics consultations address conflict around the appropriateness of CPR. Grieving family members may insist on interventions that run contrary to health professionals' sense of their responsibility to protect patients from harm. For example,

TABLE 5. Consultation characteristics of ethics committee consultations, 2007-2013 (N = 310)

Variable	Consultations	
	No.	%
Average number of days hospitalized prior to consultation: 20.0±27.4		
Consulting service		
Internal medicine (including Oncology)	175	56.5
Surgery	54	17.4
Neurology or neurosurgery	49	15.8
Anesthesia	12	3.9
Palliative care	10	3.2
Other	10	3.2
Role of requestor		
House staff, nurse practitioner, or attending phys.	212	68.4
Staff nurse	46	14.8
Clinical nurse specialist or nurse director	29	9.4
Social worker	9	2.9
Other	14	4.5
Reason for consultation as identified by requestor		
Requesting moral support or affirmation of actions	130	41.9
Surrogates desire more treatment than team believes appropriate	128	41.3
Clarification of patient's values and preferences	100	32.3
Assistance identifying appropriate surrogate	72	23.2
Assistance interpreting or applying hospital policy	62	20.0
Disagreement among family members/surrogate	35	11.3
Assistance interpreting advance care planning documents	33	10.6
Disagreement among clinicians	28	9.0
Team desires more care than patient or surrogate	24	7.7
Patient desires more care than team	18	5.8
Question raised about allocation of resources	8	2.6

(Continued next column)

TABLE 5. continued

Variable	Consultations	
	No.	%
Ethics services provided		
Supported or affirmed plans or actions	209	67.4
Identified conflict between clinicians and surrogate	131	42.3
Improved surrogate and team relationship	101	32.6
Interpreted or applied hospital policies	89	28.7
Clarified patient's values and preferences	85	27.4
Identified appropriate surrogate	67	21.6
Identified conflict among family or surrogates	42	13.5
Interpreted advance care planning documents	38	12.3
Identified conflict among clinicians	33	10.6
Administrative	15	4.8
Addressed question about allocation of resources	8	2.6
Identified additional resources		
Palliative care	58	18.7
Office of General Counsel	32	10.3
Chaplaincy	31	10.0
Psychiatry	20	6.5
Social services	18	5.8
Security	8	2.6
Parenting at a Challenging Time team	3	1.0
Number of meetings attended		
0	48	15.5
1	152	49.0
2-4	92	29.7
>4	18	5.8

Carol Jones, aged 40, mother of two elementary school children, was admitted with declining functional status and progressive dyspnea from breast cancer. Brian Jones, the patient's spouse and health-care agent, did not seem to accept his wife's prognosis or terminal condition. Up until the day of admission, Jones had been force-feeding his wife and had been demanding that she walk in order to avoid wheelchair dependence, despite her discomfort. During the hospitalization, he intervened to limit treatments aimed at pain and symptom management and insisted upon nebulizer treatments, which appeared to cause his wife discomfort.

Clinicians believed that while medical interventions had become increasingly burdensome to the patient, it was difficult for her to express disagreement with her husband. And, as the patient's health worsened, she became increasingly unable to speak on her own behalf. The ethics committee was consulted to assist the medical team in mediating ongoing conflict with her spouse, specifically his insistence on mechanical ventilation for her impending respiratory failure and CPR in the event of cardiac arrest, as well as his refusal of pain medications for her. Ethics consultants reviewed the case and decided, given the adversarial relationship between the patient's husband and the medical team, that a meeting with all of the involved parties would not be helpful. Instead, the consultants supported the clinicians with the content of the state healthcare proxy statute regarding adequate pain and symptom relief. The consultants recommended that the clinicians gently but firmly implement pain and symptom management for the patient, as specified in the Massachusetts law on healthcare proxies, Chapter 201D, Section 13, which outlines the role of the medical team in assessing and treating pain.²⁷

Additionally, because of the agreement among all of the treating physicians on the team that the patient was imminently dying, the ethics consultants recommended the patient be protected from CPR and mechanical ventilation with a do-not-resuscitate (DNR), do-not-intubate (DNI) order. They supported the use of a DNR/DNI order without the consent of the patient's husband, in accordance with the hospital's Life-Sustaining Treatment Policy.²⁸ They also recommended that the medical team continue to support the spouse in his grief. Ethics consultants suggested a compassionate but firm approach in discussing the necessity of relieving pain and suffering and of avoiding treatments that appeared to be both nonbeneficial and harmful in the context of the patient's values and clinical condition.

Based on the ethics consultants' recommendations, the physicians and nurses felt supported in compassionately setting limits in their care of the patient. Professional society guidelines, hospital policy, and state law, as documented in the ethics consult note, provided a rationale for not offering CPR and for providing adequate pain and symptom relief to a dying patient. Once the attending physician reviewed these decisions with the patient's husband, he accepted their recommendations, and his wife died peacefully a few days later.

Assistance identifying the appropriate surrogate decision maker. Some patients present with a life-threatening condition that cannot be reversed, and lack decision-making capacity, but have no surrogate with whom clinicians can discuss goals of care. This was the case for Patricia Sellers, aged 84, who was transferred from a rural hospital in a neighboring state, initially without accompanying family or friends. She had been diagnosed with an aggressive gynecological cancer and was referred for an opinion regarding treatment. The multidisciplinary oncology team thought that surgery, chemotherapy, and radiation would not be beneficial, given her malnutrition and poor functional status. Prior to her admission, Sellers had signed a healthcare directive, naming Cathy Marshall, a friend, as her healthcare agent; however, Marshall did not feel comfortable making decisions for Sellers without her estranged daughter, Joan Sellers, being involved. The patient's daughter had visited and, despite a strained mother-daughter relation, was open to being part of her mother's care. The attending surgeon requested an ethics consult with the question: Who was the appropriate decision maker for the patient? The need to identify a surrogate was urgent, given that the patient's life expectancy was less than a month.

The ethics consultant's recommendations included a team-patient-family meeting and efforts to improve the patient's mental status—if possible—so that she could confirm her wishes. Fortunately, she regained decision-making capacity. A meeting was held at her bedside, with the goal of supporting her by respecting her self-determination and creating a plan for high-quality end-of-life care. The ethics consultants encouraged the physicians to be frank about the patient's clinical situation—aggressive, advanced cancer with limited life expectancy—so she could plan accordingly. Together, the team, ethics consultants, and the patient developed an advance directive stating that she would not want aggressive treatment such as resuscitation or admission to the ICU, and would prefer that the focus be on pain and symptom relief.

Further discussion with Sellers led to a compromise—both her friend and daughter would work together to carry out her wishes as expressed in her advance directive when she was no longer able to speak on her own behalf. Marshall embraced the idea of collaboration with her friend's daughter, to ensure the patient's wishes. As Sellers declined, the palliative care service was consulted to assist, with the involvement of both the daughter and Marshall in further planning. The ethics consultants and gynecology-oncology clinical team were satisfied that the patient would be supported by her friend, her daughter, and palliative care professionals in end-of-life transitions.

The family persistently requests life-sustaining treatment that is deemed to be nonbeneficial or harmful. Thomas Jackson, 86 years old, was brought to the Emergency Department after being found unresponsive at home, where he resided with his daughter. His general health had been declining, and he had had frequent hospitalizations in the past six months. Diagnostic imaging revealed a large intracranial hemorrhage and multiple embolic ischemic strokes. He was admitted to the hospital, but, despite aggressive interventions, was eventually diagnosed as being in a persistent vegetative state. His family requested that a tracheostomy tube and a gastric tube be placed, which were performed. Enteral tube feedings, however, were unsuccessful due to high residuals (some of the feedings remained in the patient's stomach, which can lead to aspiration and pneumonia). At the time of the ethics consultation, several months into his hospitalization, Jackson had no purposeful responses, only brainstem reflexes.

The neurology interprofessional team requested an ethics consult to provide advice on how to respond to the patient's daughters' and granddaughters' persistent requests for full life-sustaining treatment, including CPR and mechanical ventilation, and continued medical nutrition and hydration. The ethics consultants participated in a team-family meeting, in which the family voiced their frustrations, concerns, and questions. The attending neurologist, nurses, social worker, and ethics consultants responded nondefensively to the family's frustrations and provided clarification of previous misunderstandings. The ethics consultants emphasized that the goal was for the team and the family to reach an understanding about the patient's prognosis and what was medically and rehabilitatively possible in the context of the patient's values.

The ethics consultant talked specifically about physicians' and nurses' concerns that CPR and mechanical ventilation would not be consistent with

the patient's values or best interests. The family listened and concurred that these interventions would be more harmful than beneficial. The neurology team members also spoke of the patient's inability to tolerate tube feeding, worsening respiratory status, and significant edema and skin breakdown from the administration of intravenous fluids. His family did not want to give up on retrying tube feeding, saying, "Where there is life, there is hope." The attending physician offered chaplaincy support, which the family accepted, as well as palliative care consultation, which the family agreed to consider.

The meeting ended with an improved but not perfectly shared understanding. The ethics consultants offered an explicit summary statement that both the team and family should work together to provide Jackson with care that would best dignify the end of his life, whenever it came. Unfortunately, Jackson was never able to tolerate enteral tube feedings and had a progressive decline, passing away nine days after the ethics consult. He did not return to the ventilator or have an escalation of interventions at the end of his life. Throughout his final days, his family members seemed less angry and more receptive to the hospital staff.

DISCUSSION

The objective of this study was to present comprehensive quantitative and qualitative information on seven years of ethics committee consultation at Massachusetts General Hospital, which has had one of the longest standing and most active ethics committees in the U.S.²⁹ Our primary findings include that, from using multivariate analysis, patients for whom the ethics committee was consulted were more likely to be non-White, older, and underinsured, but did not have a low income or a primary language other than English. We also found that health professionals initiated a request for ethics consultation far more frequently than patients or families did, and often because the health professionals perceived that surrogates desired more treatment than the medical team believed was appropriate. The ethics committee worked to navigate team-surrogate relationships in these cases, to apply relevant hospital policies, and to identify additional institutional resources, including social work and chaplaincy, when these services were not already following the patient.

Sociodemographic and Clinical Context

Contextualizing these results, the average age of our patient cohort was slightly older than in previ-

ously reported studies, which have ranged from 48.1 to 61.2 years, although most of the committees also saw pediatric patients.³⁰ While the gender distribution of the consult patients was largely consistent with prior studies, with slightly higher numbers of men, to our knowledge there are no previously reported studies on U.S. ethics committees that include detailed demographic data with which to compare our data on primary language, country of origin, median household income, insurance status, education, or functional status.

Why were underinsured, non-White, and elderly patients overrepresented in ethics committee consultation, compared to the general inpatient population, even after adjusting for household income and primary language? A complete answer to this question depends on whether these groups are disproportionately represented in specific types of consultation cases or whether they are more generally disproportionately represented. For example, it may be that underinsured patients are more likely to have consults for disagreements regarding life-sustaining treatment, because, as some authors have speculated, ethics committees are consulted to limit expensive treatment in these cases.³¹ Alternatively, patients who are homeless or socially marginalized are less likely to have adequate insurance and are more likely to lack surrogate decision makers in the event of a catastrophic medical illness. In our data, these patients would be overrepresented because the ethics committee is consulted to assist in decision making about life-sustaining treatment for these patients.³²

Similarly, the explanation for the disproportional representation of non-White patients also likely depends both on the specific racial or ethnic group, the degree of acculturation, and the type of consultation. It may be that, as some authors have speculated, distrust of a historically untrustworthy healthcare system among non-White patients, particularly Blacks, the largest minority group in our cohort, generates disagreement about life-sustaining treatment that is protracted enough to require ethics committee involvement.³³ Or it may be that consult questions on the use of life-sustaining treatment to keep a patient alive until overseas family members can obtain visas, requests to repatriate patients, or disagreements between family members, at the bedside and at a distance, are more common in non-White patients, all of which might explain their disproportionate representation. Consultation requests also may be driven, in part, by the medical team's lack of familiarity with some cultural and religious norms and beliefs.

We suspect that the higher percentage of patients older than 65 in our cohort, compared with the general adult inpatient population, also has multiple explanations. Most obviously, since our committee focuses on life-sustaining treatment, and older patients are more likely to require life-sustaining treatment, they are more likely to have ethics consults. In addition, elderly patients are at higher risk for falling into a state of diminished capacity, which may lead to consultation for questions about their ability to consent, or to refuse life-sustaining treatment, or about who is the appropriate surrogate decision maker.³⁴ Clinicians may also be more concerned about the burdens of life-sustaining interventions for elderly patients who have poor reserves or about performing CPR in this population, which may trigger ethics committee consultation when these conflicts cannot be resolved easily.³⁵

Ultimately, the results of our comparative analysis with the general inpatient population should be taken as hypothesis-generating, and requiring further confirmation and exploration at other medical centers. Regardless of the specific etiology for the disproportionate representation of certain groups, it is important for any hospital ethics committee to understand how the patients for whom they are consulted differ from the general inpatient population. Understanding how patients in ethics consults differ from other patients in the hospital, and from the committee members themselves, should lead to reflection on how the consultants evaluate and weigh patients' and their surrogates' ethical claims on the established medical community. The identification of specific patterns in consultation should also encourage committees and consultants to interrogate and address issues of systemic or implicit bias in their own perspectives. This is particularly true as ethics committees are increasingly called upon to serve as a forum for the extrajudicial resolution of conflict regarding life-sustaining treatments. Committees that lack the diversity of their consultation population risk exacerbating unrecognized discrimination or biases inherent in the healthcare system and being perceived as biased, particularly against vulnerable minority populations.³⁶ We have, however, previously reported that neither age nor non-White race was associated with MGH ethics consultants' recommendations to withhold CPR without a surrogate's consent.³⁷

With regard to the clinical characteristics of our cohort, the percentage of patients hospitalized in the ICU was consistent with the wide range reported in previous studies (15 to 70 percent), although this appears to be slightly higher than average.³⁸ The

overall severity of illness was also slightly higher than reported by Swetz and colleagues, although the majority of patients in their cohort also had a poor prognosis.³⁹ Unsurprisingly, our in-hospital mortality rate was higher, which likely reflects that the MGH ethics committee is most often consulted for disagreement about life-sustaining treatment. Finally, although there are limited data from prior studies on the prevalence of advance care planning (ACP) documents, similar to that reported by Bruce and colleagues, we found a very low overall prevalence of living wills or medical directives in our cohort.⁴⁰ Only a little more than half of our patients had an official healthcare proxy document, which is consistent with other studies of healthcare proxy documentation among the seriously ill.⁴¹ Whether increasing utilization of ACP documents may reduce conflict regarding life-sustaining treatment and ethics consultation, as some have hoped, remains unclear.⁴²

Consultation Context

As noted in previous studies, the majority of requests for consultation are made by physicians, although, in our experience, consultation requests are often generated from multidisciplinary consensus regarding the need for ethics involvement, with physicians serving as the primary source of that request.⁴³ The percentage of consultation requests from patients or families was lower than other large multicenter studies have reported, which range from 3.0 to 29.0 percent.⁴⁴ Until 1994, only attending physicians at our institution could request an ethics consultation, and this may partially explain the low rate of consultation requests made by patients or family members. Alternatively, unlike our ethics committee—whose primary role is to mediate conflict over life-sustaining treatment in adults—committees with a broader scope may receive more requests for consultations from patients or family members for concerns such as appropriate treatment for newborns or minors. The percentage of requests from nursing (24.2 percent) was consistent with the wide range reported in previous studies (15.0-37.0 percent), although we again emphasize that, for many of the consults requested by physicians, physicians were often acting in concert with nursing and other health professionals.⁴⁵

The most common reasons that ethics consultations were requested were disagreement between clinicians and surrogates, and most often regarding whether it was appropriate to continue or initiate a new life-sustaining treatment, including CPR. This is consistent with multiple prior studies conducted

in the 1980s and 1990s that reported that ethics committees are frequently consulted about withdrawing or withholding treatments, despite surrogates' requests.⁴⁶ It is much less common that contemporary ethics committees are consulted for the purpose for which they were originally felt to be most suited, namely, to comment on the appropriateness of withdrawing life-sustaining treatment at the request of a surrogate for an incompetent patient.⁴⁷ The percentage of cases involving conflict regarding life-sustaining treatment in our cohort is consistent with recent contemporary reports at similarly sized medical centers.⁴⁸ As with other U.S. studies, explicit questions about resource allocation made up a very small portion of overall cases, unlike in Europe, where this type of consultation may be more common.⁴⁹ We do note, however, that informal questions about the appropriate use of resources, particularly ICU beds, was not uncommon during some consultations. Finally, because of the primary focus of the MGH ethics committee, there were no requests to address reproductive technology, research protocols, or novel transplantation techniques, which are addressed by other committees.⁵⁰

With regard to the role of the ethics consultants, in about two-thirds of the cases they provided guidance on the ethical appropriateness of a specific plan of care, which typically involved identifying and mediating conflict between health professionals and surrogates. In a significant number of cases (28.7 percent), the ethics consultants referenced a specific hospital policy as part of the consultation process. This indicates the importance of having institutional policies on ethical issues such as decision making for unrepresented patients, the appropriate use of life-sustaining treatment, and palliative sedation. Finally, ethics consultants often identified additional resources. Examples of the general roles these services played include social work and chaplaincy for support and exploration of patient's and families' values and beliefs, psychiatry and the Office of General Counsel in cases of capacity and surrogate decision making, and palliative care in cases requiring longitudinal support and symptom control for seriously ill patients. In contrast with other recent studies, we found that a majority of consultations could not be addressed with a brief phone or email conversation, and more than a one-third required two or more team or team-family meetings.⁵¹

Implications for Ethics Consultation and Quality Improvement

Conducting this retrospective review has had several implications for our ethics consultants and

broader committee. First, by quantifying the number of consults and meetings attended, trends over time, and diversity among the hospital services utilizing the ethics committee, we have been able to produce an annual report of committee consult activities. The availability of these data have allowed us to approach the hospital administration and successfully secure additional resources for the committee, including dedicated funding for ethics consultation. Understanding the “high utilizers” of ethics consultation has also reinforced our commitment to providing ethics education outside of individual consultation cases. For example, the large proportion of consult requests from the various ICUs has supported our continuation of multidisciplinary ICU ethics rounds, which provide a regular opportunity for informal discussion of ethics questions that arise during routine patient care. We have also begun to integrate more formal presentations on relevant topics such as decision making for patients without surrogates and critical care society guidelines on resolving conflict over potentially inappropriate treatment into these rounds.

Second, a better understanding of the sociodemographics of the ethics consult population has reinforced our committee’s commitment to diversity of membership. We have intentionally extended membership invitations to individuals in the hospital community who identify as being of similar backgrounds to patient groups who have been disproportionately represented among ethics consultants. In so far as possible, we aim to have a diversity of professional and personal backgrounds so as to provide a range of perspectives during the actual ethics consultations and in the subsequent full committee consult review. We have also continued to recruit committee members from the community and to rely on the input of a local community-based ethics committee when we consider ethics-related hospital policy. Third, we have used the database to review how consultants apply specific hospital policies, including cases regarding disagreement about the appropriateness of CPR.⁵² As a result of this study, we have further refined and clarified our hospital policy regarding the appropriate process for not offering CPR to imminently dying patients when there is disagreement about their DNR/DNI status.

Going forward, our goal is to build from the database to improve the quality of the consult process through targeted surveys of health professionals, patients, and families and their satisfaction with the consultation process. Having a pre-existing framework for categorizing consults for research purposes will allow us to target such quality improvement

efforts to specific types of consult cases. Ultimately, we would like to quantify the impact of ethics consultation on specific outcomes, such as treatment intensity scores, quality of death, and family bereavement, projects that will now be easier to research using the research infrastructure we have developed. Based on our experience, we encourage other committees to develop or utilize pre-existing consultation categorization models to investigate the utilization, sociodemographics, and outcomes of their consults.⁵³

Limitations

Although this is one of the largest single center studies of ethics committee consultation to date, and the first to perform a comparative sociodemographic analysis with the general adult inpatient population, our study has several limitations. First, the ethnic/racial composition of our catchment area will not reflect that of many other hospitals. Second, because the MGH ethics committee has helped to generate and refine institutional policies and is very active, our results may not be generalizable to less frequently consulted committees or to hospitals without organizational policies on life-sustaining treatment. Third, regarding our comparative analysis, there were several confounding variables, including severity of illness, functional status, and country of origin that were not available in the RPDR database. We were not readily able to assess whether, for example, non-White patients in our hospital were sicker than White patients. Given, however, that ethics consults are more likely for sicker patients, it may be that severity of illness and not race explains why non-White patients were disproportionately represented among ethics consults. Fourth, we did not have sufficient cases to perform an analysis of how trends in consultation requests and patients’ clinical and sociodemographic characteristics changed over time.

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27. *Ibid.*

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