

Evaluating the Inpatient Pediatric Ethical Consultation Service

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ABSTRACT

OBJECTIVES: Pediatric ethical consultation services (ECSs) have been proliferating at medical centers, with little data available on evaluating their implementation. The objective of this study was to evaluate the pediatric ECS and understand the ethical issues occurring within a single quaternary-level pediatric hospital.

METHODS: A retrospective chart review of documented ethics consultations at a large pediatric hospital from November 2010 to November 2013 was performed and data was abstracted per the US Department of Veterans Affairs' Domains of Ethics in Health Care. An anonymous, prospective survey regarding ethical issues encountered was distributed electronically to ~3500 inpatient staff from November 2013 through January 2014. Ethical domains, demographics, feelings of distress by staff, and location of occurrence data were collected. These data were compared with formally documented ethics consults from the retrospective chart review and ECS activity during the same period.

RESULTS: A total of 47 ethics consults were documented between 2010 and 2013, primarily in the domains of end-of-life care (19; 40%) and shared decision-making (17; 36%). Sixty-three staff members (92% female; 42% nurses; 20% attending physicians) logged an encountered ethical issue between November 2013 and January 2014, corresponding to only 5 documented ethics consults in the same time period. Domains included end-of-life care (18; 28.5%), shared decision-making (13; 20.6%), everyday workplace (11; 17.4%), professionalism (8; 12.6%), and resource allocation (7; 11%). Eighty-one percent of subjects reported personal or professional distress.

CONCLUSIONS: On the basis of this single-center study in which we reviewed formal documentation, we determined that formal pediatric ECSs are underused, particularly for ethical domains that cause staff members moral distress.



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Encountering ethical issues is common in the practice of pediatrics.^{1–5} Ethical values are embedded within every clinical encounter because caring for patients involves both scientific and moral consideration. Medical providers in pediatric hospitals frequently encounter ethical conflicts because of high patient volume, high medical complexity, and multiple staff interactions.^{3,4,6} Ethics consultation is a widely endorsed mechanism for resolving such possible conflicts, facilitating communication, and easing moral distress in health care.^{7,8} Authors of a study published in 2007 surveyed more than 500 adult hospitals and demonstrated that an ethics consultation service (ECS) was rarely used, with a median of only 3 cases per year for each hospital.⁹ This underuse is likely multifactorial.¹⁰ Limited data exist for ECS use in pediatric centers.¹¹ In this study, we aim to evaluate the use of an ECS at an academic pediatric medical center. We hypothesized that the ECS is underused relative to the number of ethical issues perceived and reported by hospital staff.

METHODS

In the first part of this 2-part study, we retrospectively evaluated the ethical issues documented through consultation by the hospital's ECS. This was to establish the baseline consultation rate (consults per year) and the distribution of ethical domains addressed during consultation. The ECS was composed of a formal ethics committee of at least 20 individuals and 4 ethics consult teams. These teams were led by 4 salary-supported ethics hospital staff. ECS includes both formally and informally trained staff and community members of varying backgrounds.

In the second part, we prospectively asked members of the hospital staff to report when they encountered an ethical issue during inpatient care. The hospital staff includes more than 4500 individuals. We simultaneously collected data on the number and content of formal ECS consults. Fisher's exact test and χ^2 analysis were conducted to compare the distribution of ethical domains between retrospective chart review of ECS activity and the

prospective staff report of ethical issues. The study was approved by the University of Colorado Institutional Review Board (COMIRB 13-2112).

Retrospective Chart Review of ECS Consults (November 2010–November 2013)

We conducted a retrospective electronic chart review of all ethics consultations documented by the ECS between November 2010 and November 2013. Data entry into REDCap for each consult included demographic information and a description and ethical categorization of the event based on the US Department of Veterans Affairs' Domains of Ethics in Health Care.^{7,12} These categories included the following: shared decision-making with patients, ethical practices in end-of-life care, patient privacy and confidentiality, professionalism in patient care, ethical practices in resource allocation, ethical practices in business and management of the hospital, ethical practices in research, ethical practices in everyday workplace, ethical practices at the beginning of life, and multiple areas and/or other.

Prospective Survey of Ethical Issues Encountered by Inpatient Health Care Staff (November 2013–January 2014)

Data collection occurred between November 1, 2013 and January 31, 2014. A REDCap survey, similar to the retrospective study noted above, was developed by 2 members of the salary-supported ethics hospital staff, the senior author (J.A.F.), and the first author (K.W.) (Supplemental Figure 2). The REDCap-based survey was and is posted at www.pedsethics.com. All inpatient staff members were anonymously invited to participate and consent to the study. Recruitment was conducted through posting flyers in inpatient units, using e-mail distribution lists, and asking hospital divisions to remind their staff. The electronic reminders were sent at least monthly during the course of the study. Staff members were asked to anonymously enter information into the REDCap site regarding any ethical issues they encountered during their routine inpatient activities. Staff also reported if they felt any professional or

personal distress regarding the issue they reported. An electronic consent was required before participation.

Prospective Review of Formal Ethics Consults (November 2013–January 2014)

From November 1, 2013 to January 31, 2014, formal ECS consults logged were recorded in the REDCap database. Data regarding the domains and nature of the consults were manually abstracted from the medical record.

RESULTS

Retrospective Chart Review of ECS Consults (November 2010–November 2013)

Forty-seven ethics consults were documented in the electronic medical record during this 3-year period (average of 15.7 consults per year). The individual or service who requested the consult was not documented. The location of consults included the PICU (11 out of 47; 23.4%), general pediatrics (9 out of 47; 19.1%), NICU (8 out of 47; 17%), other locations, including the psychiatric unit (6 out of 47; 12.7%), gastroenterology (4 out of 47; 8.5%), hematology and oncology (4 out of 47; 8.5%), pulmonary medicine (3 out of 47; 6.4%), and the cardiac ICU (CICU) (2 out of 47; 4.2%). The most common ethical domains addressed were end-of-life care (19 out of 47; 40%) and shared decision-making (17 out of 47; 36%). Other domains addressed included resource allocation, professionalism, and everyday workplace. Seven (14.8%) ethics consults addressed other and/or multiple areas.

Prospective Survey of Ethical Issues Encountered by Inpatient Health Care Staff (November 2013–January 2014)

Sixty-three staff member responses were logged as an anonymous ethical encounter. Because of the institutional review board–required anonymous nature of this study, multiple responses from the same subject were possible. Repeat responses could not be delineated from the study design. One subject did not sign their consent and was excluded. The respondents

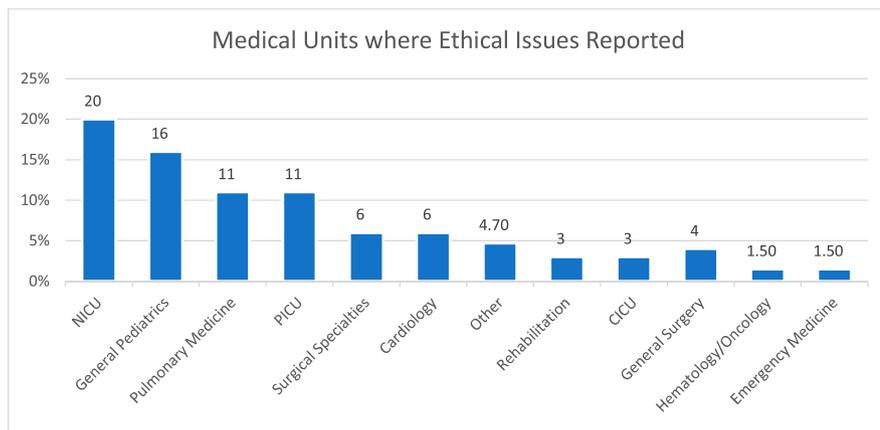


FIGURE 1 Medical units where ethical issues were reported.

were overwhelmingly female (58; 92%), and 67% were between the ages of 18 and 40 years. The cohort represented 27 (42%) nurses, 13 (20%) attending physicians, 7 (11%) resident physicians, 5 (7.9%) occupational therapists, 4 (6.3%) other or no response, 3 (4.7%) fellow physicians, 3 (4.7%) social support staff, and 1 (1.5%) clinical assistant. The majority were Christian (65.1%). Other faiths were as follows: agnostic (9.5%), Jewish (7.9%), and atheist (6.3%). Forty-one percent reported having no previous ethics education. Members of the NICU and general pediatrics teams reported most of the ethical issues (Fig 1).

End-of-life care issues were the most frequently reported ethical domain (18; 28.5%). Other common ethical domains were shared decision-making (13; 20.6%), professionalism (11; 17.4%), and resource allocation (8; 12.6%). Infrequent ethical domains reported were privacy, research, and everyday workplace issues. Physicians, nurses, and other hospital support staff identified similar ethical issues, although the majority of issues were reported by

nurses. The majority of respondents (81%) reported personal or professional distress from the ethical situation they encountered.

Some ethical domains were reported more frequently by specific types of health care staff and practice areas. For example, 40.7% of the 18 of end-of-life care events were reported by nursing staff, 30% of 13 issues in shared decision-making were reported by attending medical staff, and 43% of the 8 issues regarding resource allocation issues were noted by resident medical staff. Fellow physicians, social support staff, and clinical assistants reported professionalism. Critical care services noted end-of-life care (NICU 42%, PICU 57%, and CICU 100%), and general pediatrics often reported shared decision-making (40%).

Prospective Review of Formal Ethics Consults (November 2013–January 2014)

Five formal ECS consults were documented during this time period compared with 63 ethical issues perceived and reported by hospital staff. ECS consults primarily addressed shared decision-making

(3 consults on rehabilitation, pulmonary, and cardiology services) and end-of-life care (2 consults in the NICU and in general pediatrics) issues. It is unknown if the ECS consults were performed for the same patients whom staff reported perceived ethical issues because of the anonymity of data collection.

Comparison of Prospective and Retrospective Studies

The retrospective chart review (November 2010–November 2013) yielded an ECS consultation rate of 15.7 consults per year, whereas the prospective ECS study (November 2013–January 2014) revealed ~20 consults per year (5 consults per 3-month period). The 2 most frequently reported domains (end-of-life and shared decision-making) were similar in the 2 studies, but the overall domain distribution of ethical domains was significantly different ($P < .05$) (Table 1). With the prospective survey, we found additional ethical domains of activity that were not usually dealt with by the ECS in the retrospective study. Because of the small number of ECS consults during the prospective study and limited statistical power, additional statistical evaluation could not be performed.

DISCUSSION

During a 3-month period, 63 ethical issues were encountered in routine clinical care that caused personal or professional distress. However, only 5 formal ECS consults were documented during the same time period. The ECS usage rate during the study period was similar to that of the previous 3 years.

Ethical issues reported by hospital staff were similar to issues discussed during formal ECS consults, but overall distribution

TABLE 1 Comparison of Distribution of Ethical Domains Between Prospective and Retrospective Studies

	End-of-Life Care	Shared Decision-Making	Professionalism	Research Practices	Patient Privacy	Multiple Categories and/or Other	Confidentiality	Everyday Workplace	Resource Allocation
Prospective study respondents, ^a n (%)	18 (28.5)	13 (20.6)	11 (17.4)	2 (3.2)	3 (4.7)	7 (11)	0	1 (1.6)	8 (12.6)
Retrospective study respondents, ^a n (%)	19 (40)	17 (36)	1 (2.1)	0	0	7 (14.9)	0	1 (2.1)	2 (4.2)

^a $P < .05$.

was significantly different. Primary ethical concerns were related to shared decision-making and end-of-life care. Hospital staff also identified other ethical issues including professionalism, patient privacy, and resource allocation, which did not result in formal ethics consults. This likely created the difference in distribution. Certain medical units and specialties seemed to encounter and report different ethical domains, such as nursing reporting end-of-life care and fellows and social support staff reporting professionalism.

Ethics consultation has been used for over 20 years as a method to resolve ethical issues that are routinely encountered by health care staff.⁹ By using ethics consultation, stays in the ICU are shortened and costs are decreased.¹³ The Joint Commission has mandated that hospitals develop methods (including expert consultation) to deal with ethical dilemmas; however, 95% of general hospitals could not agree on quality standards regarding ethics consultation.^{9,14} ECSs have tried to improve training and quality, but this problem has continued to stagnate.^{8,10} In a study published in the American Journal of Bioethics, the authors noted that less than half of ethics consultants have formal training, and only 1 in 20 has a bioethics certification or graduate degree.⁹ In a 2015 study, Morrison et al⁸ showed that ECSs continue to be underused nationally, and pediatric staff members are lacking ethics training. If health care staff training regarding the use of the ECS could be improved, this could potentially support an effective implementation of ECSs in pediatric hospitals. Although the ECS in this study contains individuals with protected time and formal training, authors of studies have demonstrated that ethics committees and consultation services are underfunded.¹⁵ In data from this study regarding ethical domain activity and others, it is shown that improving training, awareness, use, and funding for ECSs could potentially improve patient care, and it is suggested that training is needed.^{2,11,16–18}

The limitations of this study include the following: (1) the retrospective chart review was limited by a lack of standardized

documentation, and both the number of consultations and the number of ethical domains addressed may be underreported or inadequately represented; (2) selection bias in the staff members who voluntarily reported ethical dilemmas and possible underreporting or over-reporting of ethical dilemmas that occurred during patient care; and (3) the underreporting of the usage rate of ECS consults given that informal consults occur during situations like ethics rounds and nursing liaison visits.

CONCLUSIONS

ECSs were underused compared with the number of ethical issues perceived and reported by hospital staff in a pediatric medical center. Further work is needed to improve staff awareness of ECSs, ECS documentation, and programs to address the personal and professional moral distress staff members report around ethical issues.

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