How Do I Get an Ethics Consultation? Comparing Barriers to Ethics Consultation in Pediatric Inpatient and Outpatient Settings

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ABSTRACT

Objective

Ethics consultations are important avenues for the discussion of complex decision making in the clinical setting. Few studies have looked at barriers to ethics consultation in the pediatric setting, especially in the outpatient setting. This study aimed to characterize the utilization of ethics consultation at a pediatric nonprofit healthcare system, with a particular focus on how medical providers' perceptions inform requests for ethics consultation in both inpatient and outpatient settings.

Methods

We surveyed healthcare providers and asked about their previous experiences with the ethics consultation service, potential barriers to obtaining a consultation, and factors that would make them more likely to request a consultation in the future. The survey was distributed electronically via email.

Results

Of a total of 598 providers, 139 completed the survey (a 23 percent response rate). Respondents were mostly physicians and nurse practitioners from critical care, hematology/oncology, or outpatient general pediatrics. In the inpatient setting, identified barriers to ethics consultations included not wanting to upset the patient or family, not wanting to upset colleagues, and not knowing if they were dealing with an ethical issue. In the outpatient setting, respondents reported they did not know how to request a consultation or if they were allowed to request a consultation as outpatient providers.

Conclusions

Providers identified several barriers to ethics consultation, and barriers differed according to clinical setting. These findings highlight the need to address general barriers to pediatric ethics consultation, including education on the logistics of an ethics consultation and how to mitigate unease about initiating a consultation, but also practice-specific barriers as experienced by inpatient and outpatient providers.

INTRODUCTION

Across U.S. hospitals, ethics consultations are an important avenue for making complex

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decisions within patient care.[1,2] Although it's growing, the body of literature that addresses the role of clinical ethics consultation within pediatrics remains limited, and despite the wide breadth of situations that could precipitate a need for an ethics consultation in the pediatric setting, relatively few consultations take place.[3] Studies suggest that this paucity of pediatric ethics consultation could be due to clinicians' lack of comfort to address these concerns directly, or a lack of other platforms that address ethical concerns, or, more concerningly, a perception that ethics consultations will upset colleagues or are not helpful.[4,5] When ethics consultations do take place in the pediatric setting, the reasons consultation are requested vary, and include topics such as withdrawal of life-prolonging measures or other end-of-life concerns, disagreements within a healthcare team or between a healthcare team and family/patient, and respect for a child's emerging autonomy.[4-6]

Even more limited is research that addresses the role of ethics consultation in the outpatient setting. The ethical concerns addressed in that setting may differ from those common to the inpatient setting. For instance, the few studies that exist describe the outpatient topics of ensuring child welfare in complex social situations, longitudinal therapeutic relationships with caregivers, or topics related to privacy or confidentiality.[7] Outpatient ethics consultations may also take on more of a preventative role, such as the initiation of discussions around difficult decisions that are expected to arise over the course of treatment or decisions around preventative care such as vaccines.[8-10]

The goal of this study was to learn about how ethics consultations at a pediatric nonprofit healthcare system are currently utilized and how the views of physicians, nurses, and other clinicians inform their decisions on whether or not to initiate an ethics consultation. We were specifically interested in how the clinical setting (inpatient versus outpatient) affected perceived barriers to and utilization of ethics consultation. When we can identify specific barriers, and we can target education and other process improvements to better assist medical providers in their specific practice settings, we can move from merely a reactive consultation mechanism to a more proactive service to support clinicians, patients, and families.

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THE STUDY SETTING AND ETHICS CONSULTATION PROCESS

This study was conducted at Children's Wisconsin (CW), a private, independent, not-for-profit healthcare system that includes two hospitals (with a total of 340 beds) and more than 70 outpatient clinic settings. CW is also a major teaching affiliate of the Medical College of Wisconsin. The ethics consultation service averages about one consultation per month (15 consultations in 2019; 12 in 2020). Any hospital employee, patient, or family member may request an ethics consultation seven days a week, 24 hours a day, by paging the on-call ethicist. To be able to speak with the involved parties, we cannot perform anonymous consultation. However, staff who wish to remain anonymous may ask their leader to request a consultation on their behalf. In 2019 and 2020, one consultation

request came from a parent. The remainder were initiated by a member of the healthcare team.

The ethics consultation process at CW uses a small-team model. There are currently five team leaders who are physicians, ethicists, and/or other staff with advanced training in healthcare ethics at either the masters or graduate degree level. When a consultation is requested, an ethics consultation team leader briefly discusses the case with the requestor to clarify concerns and then reviews the patient's chart to better understand the medical and psychosocial features. The committee member can then meet with the family or, if appropriate, coordinate an interdisciplinary team meeting to discuss recommendations and develop an action plan. Rarely (and typically for an urgent matter) the consultation will only consist of a conversation between the team leader and the person who requested the consultation. Consultations are later discussed with the full ethics committee for review and, if needed, additional guidance.

This process applies to requests in both inpatient and outpatient settings. When a consultation is requested in an outpatient setting, the team leader may perform the consultation in person or via phone or web conference, as appropriate.

METHODS

The recruitment pool consisted of 598 employees of CW and included a mix of 135 learners (resident and fellow physicians), 78 nurses, and 385 other providers (attending physicians and advanced practice providers). These employees practiced in either inpatient or outpatient settings, or both. The decision to contact a more targeted representative sample was made in an effort to avoid institutional survey fatigue and to increase response rate.

To inform development of the survey, we conducted a literature review and performed a qualitative thematic analysis of the ethics committee meeting minutes to identify common consultation themes from 2019 to 2020. Our survey underwent pilot testing prior to finalization and was distributed in June 2023

TABLE 1. Participants' demographics by healthcare providers' setting: inpatient versus outpatient (*N* = 139)

	Inpatient or both settings	Outpatient only
Primary position	*n* = 85	*n* = 54
Attending	44	33
Fellow	12	3
Nurse	10	2
Nurse practitioner	16	15
Resident	2	0
Other	1	1
Time at CW	*n* = 85	*n* = 54
< 1 year	3	4
1 – 5 years	28	10
6 – 10 years	17	12
11 – 20 years	26	15
> 20 years	11	13
Formal training in bioethics	*n* = 85	*n* = 54
No	66	43
Yes	19	11

TABLE 2. Healthcare providers' primary unit by clinic setting

	Inpatient or both settings (*n* = 85)	Outpatient only (*n* = 54)
Primary field/unit		
General pediatrics	—	30
Urgent Care	—	13
Child development	—	1
Surgery	—	1
Hematology/Oncology/ Bone Marrow Transplant	17	4
Acute care/Hospital medicine	8	—
Pediatric Intensive Care Unit	26	—
Neonatal Intensive Care Unit	16	—
Clinical Resource Unit*	4	—
Other**	14	5

* Clinical Resource Unit = nursing able to float throughout multiple units

** Includes Safety Enterprise, Administration, and other clinicians without a primary field/unit

using the online survey platform Qualtrics. The survey was optional and anonymous, and the Medical College of Wisconsin Institutional Review Board (IRB) determined the study was exempt from IRB oversight.

ANALYSIS

We used descriptive statistics to analyze the findings and conducted qualitative thematic analysis of the free-text responses to find and identify meaningful patterns in the data.[11] We analyzed barriers to pursuing a consultation, the benefits of consultation, and factors that would make individuals more likely to request a consultation when needed in the future. Particular attention was given to the barriers and facilitators to ethics consultation in outpatient settings.

RESULTS

Participants' Characteristics

Of the 598 employees invited to participate, 139 completed our survey for a final response rate of 23 percent. The majority of respondents were attending physicians or nurse practitioners; nurses and fellow physicians were also represented (see table 1). The Pediatric Critical Care Unit and the Hematology/Oncology/Bone Marrow Transplant Units were heavily represented, as were the Neonatal Intensive Care Unit and outpatient primary care sites (see table 2). Almost half (45 percent) of the respondents reported they worked only in the inpatient setting, and 39 percent reported they worked only in the outpatient setting; the remainder of respondents reported they worked in both inpatient and outpatient settings. The majority of respondents (68 percent) were very familiar with CW, as they had worked there for at least five years. Only seven respondents had been employed by the hospital for less than a year. Most respondents (78 percent) reported they had no training in bioethics.

TABLE 3. Topics of ethical concerns reported from the outpatient setting in order of the most commonly reported

Parent refuses treatment or family is noncompliant
Child cared for in a concerning social situation (other than abuse or neglect)
Adolescent reproductive care
Parents and/or patient in disagreement with each other
Provider is pressured to prescribe/family demands treatment
Sharing information with guardian
Vaccine refusal
Question of guardianship
Concern for family's understanding level/ability to provide care for patient
Family untruthful about alternative care
Inappropriate parent behavior
Lack of assent
Patient is dating a provider's family member

Interactions and Experiences with Consultation

Interactions and experiences with ethics consultations differed between providers who only worked in the outpatient setting compared with providers who had inpatient responsibilities. Whereas a majority (97 percent) of providers with inpatient responsibilities reported they were aware that an ethics consultation service was available to them, only 63 percent of exclusively outpatient providers knew the consultation service was available. More than half (65 percent) of the providers with inpatient responsibilities reported previous interaction with the ethics consultation service in some capacity. Conversely, most outpatient-only providers (83 percent) had never interacted with the consultation service. A higher proportion (65 percent) of outpatient-only providers compared with 16 percent of inpatient providers reported that they had never needed an ethics consultation. Providers with inpatient responsibilities (41 percent) more often reported that they had seen a case in which an ethics consultation would have been helpful, but did not happen, than providers who worked only in the outpatient setting (26 percent).

Ethical Concerns in the Outpatient Setting

Of the 77 outpatient providers who worked in the outpatient setting (including those who worked in both settings), 34 percent reported they had experienced an ethical dilemma in

the outpatient setting, and 29 percent reported they were unsure whether or not they had experienced an ethical dilemma. When asked about the topics of those ethical concerns, or potential ethical concerns, parents' refusal of treatment and navigating complex social situations (such as suspected child abuse or neglect) were the most commonly reported. The topics of adolescent reproductive care, providers who shared information with guardians, vaccines, and providers who felt pressured to treat were additional concerns (see table 3). Of note, these were concerns that arose whether or not an ethics consultation took place.

None of the ethics consultations that were reviewed in our preliminary work came from the outpatient setting. The topics of the inpatient consultations in our preliminary review were congruent with the topics reported in other published studies.[4-6] The most commonly reported ethical concerns in the inpatient setting involved disagreement between the treatment team and patient/family, patients' best interest, nonbeneficial treatment (futility), and withdrawing or withholding life-prolonging measures.

Barriers to Ethics Consultations

Inpatient and outpatient providers reported different primary barriers to obtaining an ethics consultation (see tables 4 and 5). In the inpatient setting, the top reported barrier to consultation was not wanting to upset colleagues or supervisors. Other barriers included not wanting to upset the patient/family and not knowing if their concern was an ethical issue. In the outpatient setting, the top two barriers were logistical concerns of not knowing how to initiate a consultation and not knowing if they were allowed to do so in the outpatient setting. Not knowing if their clinical concern was an ethical issue was again reported, as was not wanting to upset others—either colleagues or the patient and family. Notably, significant portions of both outpatient and inpatient providers said that there were no barriers in obtaining ethics consultations in their practice setting.

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Benefits of Ethics Consultations

A number of themes were identified in participants' responses to the question "What did you find most helpful about the consultation?". One of the most discussed themes was appreciation for having an outside perspective from a third party. Providers also appreciated feeling supported in their decision making, the opportunity to talk through an ethical issue, access to ethical expertise, and mediation provided by the consultation. Individuals found it helpful when consultations explained relevant ethical considerations and framed the case in a systematic manner.

Recommendations to Improve Consultations

In response to "What would have made the consultation more helpful?" the most consistently mentioned theme was that participants desired firm recommendations about how to proceed and guidance to set a more concrete plan. One participant wrote: "often I have wished the ethics team would go ahead and 'take sides' even if against 'my' side. Often it has been only a sounding board and not a source of action." Similarly, participants wanted clear communication of final recommendations to be provided to all of those involved in the case, even if that a recommendation was "clearly

stating that there is no right/wrong answer and explaining why not." Others wanted consultations to fulfill more of a mediator role or wanted consultations to occur in a timelier fashion. A few noted that the consultations may have been more helpful or better appreciated if the team members who asked for the consultation had a better understanding of the purpose of an ethics consultation.

Regarding what would make a provider more likely to request a consultation in the future, the majority of responses were related to general logistical issues. Participants wanted to know how the consultation process works, how to initiate a consultation, a timeline expectation, and guidance on what would be appropriate for a consultation. Participants also reported that they would be more likely to request a consul-

TABLE 4. Top 5 selected barriers to ethics consultations by practice setting (*N* = 162)

Inpatient Setting (*n* = 85)		Outpatient Setting (*n* = 77)	
I don't want to upset colleagues or supervisors.	29	I don't know how to initiate consult.	34
I don't know if the concern was an ethical issue.	22	I don't know if I am allowed to initiate a consult.	23
I don't want to upset patient or family.	21	I don't know if the concern was an ethical issue.	17
I don't feel that consults are helpful.	14	I don't want to upset colleagues or supervisors.	13
I don't know how to initiate consult.	10	I don't want to upset patient or family.	13

NOTES
See table 5 for a full list of barriers.
Providers who worked in both settings were asked separately about outpatient barriers and inpatient barriers.

TABLE 5. Barriers to ethics consultations reported in the inpatient and outpatient settings (*N* = 162)

	Inpatient or mixed setting (*n* = 85)		Outpatient setting (*n* = 77)	
	n	%	*n*	%
I don't have access to ethics consultations.	0	0	0	0
I don't know how to initiate an ethics consultation.	10	12	34	44
I don't know if I am allowed to place an ethics consultation.	6	7	23	30
I don't know if the issue was an ethical issue.	22	26	17	22
I don't want to upset colleagues or supervisors.	29	34	13	17
I don't want to upset the patient or family.	21	25	13	17
I feel that consultations are too time-consuming.	4	5	6	8
I don't feel that consultants have adequate training/ experience.	0	0	0	0
I don't feel that consultations are helpful.	14	16	1	1
I am equipped to handle ethical situations myself.	6	7	4	5
Other barrier.*	6	7	7	9
No barriers.	24	28	18	23

NOTES
Providers who worked in both settings were asked separately about outpatient barriers and inpatient barriers.
* Other barriers included logistics such as timing of a consultation in an outpatient setting and evening or weekend availability.

tation if they had "more buy in from the rest of the team" or if consultations were considered more mainstream rather than being viewed as reserved for extreme situations.

DISCUSSION

This study identified providers' perceptions of barriers to clinical ethics consultations at a private not-for-profit pediatric healthcare system, including in the outpatient setting, as well as what would make providers more likely to request a consultation in the future.

While both inpatient and outpatient providers identified logistical barriers to requesting an ethics consultation, these were exacerbated in the outpatient setting. In the inpatient setting, 12 percent of respondents did not know how to request an ethics consultation, and 7 percent were unsure if they were allowed to do so. In the outpatient setting, these numbers rose to 44 percent and 30 percent, respectively. Barriers unique to the outpatient setting included logistical concerns such as whether consultations were timely enough to take place in the outpatient setting. This gap in providers' knowledge appears to reflect a lack of accessibility to pediatric ethics consultation services that has been found across the country and may be particularly true for outpatient providers who have been removed from the inpatient setting since training.[3] This points to the need for increased visibility of consultation services in the outpatient setting and targeted education about when and how to request an ethics consultation service. Although this education happens on an ongoing basis at CW, both for new employees and current staff, this study highlighted the need for more focused education, training, and outreach. Providing examples of appropriate topics of consultation service in the outpatient and inpatient settings is also important, as not knowing if they were dealing with an ethical concern was the third-most reported barrier to consultation in both the outpatient and inpatient settings.

In addition to logistical barriers, both inpatient and outpatient providers said their desire to not upset colleagues, supervisors, patients, or families was a barrier to requesting an ethics consultation. Although all staff and patients or families can request an ethics consultation, this barrier may be related to hierarchical power structures within healthcare and a history of criticism or censure for "calling ethics."[12-14] While our ethics team has worked diligently to frame ethics consultations as supportive rather than punitive, further work remains to shift hospital culture and perception.

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The ethical concerns identified in the outpatient setting included topics similar to those typically reported in the inpatient setting, such as parents' refusal of treatment and concerns with privacy or the sharing of sensitive information with guardians of adolescent patients. There were some differences, however, and outpatient concerns appeared to be less acute. For instance, outpatient concerns were more related to navigating complex social situations rather than related to life-sustaining treatment decisions. There may be a role for more preventative outpatient ethics discussions in settings such as chronic illness, where patients and families could get the chance to discuss potential ethical dilemmas that are likely to arise.[8] As opposed to an acute ethics consultation, these anticipatory

visits could be scheduled in advance to give all parties time to reflect on decision options in a lower stake setting. At CW, this role is frequently fulfilled by our Complex Care Team, who have ongoing conversations with the families of medically complex children, which perhaps mitigates some of the potential need for ethics consultations in the acute setting.

In this study and others, there is a general split in providers' expectations for an ethics consultation. Some providers request an ethics consultation as a mediated forum in which ethical deliberation can occur, while others desire specific recommendations arising from a structured approach.[15-17] While overall trends of clinical ethics consultations are moving towards the facilitation approach, in which the goal is to determine ethically appropriate options rather than determine the "correct" option,[18] a number of participants in this study expressed their desire for more formal recommendations or specific guidance from the consultation. However, the ethics consultation process does not always lead to specific recommendations or guidance, given the ethical complexity of the situation, even if that is what the medical team may desire. Part of the work of the consultant is to help the team identify the range of ethically appropriate options, weigh the risks and benefits of each option, foster consensus when possible, and address moral distress. Setting expectations about substantive versus procedural ethics support and the "results" of the consultation at the beginning of the consultation process is an important step in addressing this identified barrier. Thus, it is important that ethics consultants have training in communication and facilitation skills in addition to process and ethical analysis skills.[19]

This study carries several limitations, including that it was not able to survey all staff, even though all staff are able to request an ethics consultation at our hospital. We were additionally not able to get representation from all departments. However, our results do describe experiences from critical care (pediatric and neonatal) and the hematology/oncology service, and these areas constitute the majority of pediatric ethics consultations that take place in the U.S.[20] Few groups have looked at the use of pediatric ethics consultations in the outpatient setting, and our study's inclusion of this group is one of its strengths. Lastly, due to the self-reported nature of virtual surveys, there is the inherent possibility that social desirability influences responses, particularly when respondents answer questions about ethics and providing ethical patient care.

Overall, our findings suggest that inpatient and outpatient providers face different barriers to ethics consultations, as inpatient barriers are more related to attitudes surrounding consultations and outpatient barriers are more related to logistical concerns. Ethics consultation services that provide support to outpatient locations ought to be prepared to address these barriers, including ongoing education about how to access consultations. Topics of ethical concerns in the outpatient setting also differed from topics in the inpatient setting, thus consultation services ought to ensure committee members are familiar with both groups of concerns in order to best support their staff and patients.

STATEMENTS AND DECLARATIONS

No funding was received for the conduct of this study. The authors have no relevant financial or non-financial interests to disclose. The Medical College of Wisconsin Institutional Review Board exempted the study from IRB oversight.

All of the authors contributed to the study conception and design, material preparations, data collection, and analysis.

The first draft of the article was written by Julia Krantz, and all of the authors commented on previous versions of the article. All of the authors read and approved the final article.

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