

Relational, Emotional, and Pragmatic Attributes of Ethics Consultations at a Children's Hospital

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abstract

BACKGROUND: Pediatric ethics consultations are important but understudied, with little known about consultations' contextual attributes, which may influence how ethically problematic situations are perceived and addressed.

METHODS: We analyzed data regarding 245 pediatric clinical ethics consultations performed between 2013 and 2018 at a large children's hospital. Prespecified data elements included 17 core problematic issues that initiate consultations, 9 ethical considerations identified by the consultation service, and 7 relational, emotional, and pragmatic contextual attributes of the consultation. The main process measure was the cumulative consultation process, ranging from one-on-one discussions with the requestor, to meeting with the clinical team, separate meetings with the patient or family and the clinical team, or combined meeting with the patient or family and the clinical team.

RESULTS: The most-prevalent core problematic issues were intensity or limitation of treatment (38.8%) and treatment adherence and refusal (31%). Common pertinent ethical considerations were best interest (79.2%), benefits versus harms of treatment (51%), and autonomy and decision-making (46.5%). A total of 39.2% of consults culminated with a meeting with the clinical team, 9.4% with separate meetings, and 8.2% with a meeting with all parties. Common contextual attributes were discord (43.3%), acknowledged dilemma (33.5%), and articulate disagreement (29.8%). In exploratory analyses, specific contextual attributes were associated with the core problematic issue that initiated the consultation and with how the consultative process culminated.

CONCLUSIONS: Pediatric ethics consultations have contextual attributes that in exploratory analyses are associated with specific types of problems and, to a lesser degree, with the cumulative ethics consultation process.



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WHAT'S KNOWN ON THIS SUBJECT: In studies of ethics consultations across pediatric and adult settings, researchers have described recurring problematic clinical situations that lead to consultations, the pertinent ethical considerations commonly identified, and the variety of consult processes that exist across institutions.

WHAT THIS STUDY ADDS: In this study of 245 pediatric ethics consultations, we identified contextual attributes (relational, emotional, and pragmatic) that are associated with specific types of problems and, to a lesser degree, with the cumulative ethics consultation process.

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Pediatric clinical ethics consultation aims to provide guidance regarding ethically appropriate courses of action in specific clinical cases. Many published sources provide guidance for pediatric ethics consultation, including case analyses, policy statements, and textbooks.¹⁻³ Empirically based descriptions or analyses of pediatric clinical ethics consultation are scarce, because most published studies have focused on adult populations.⁴⁻⁶ Repeatedly, studies in pediatric settings note the comparatively low volume of consultations.⁷⁻⁹ Pediatric ethics consultation studies consequently have consisted of smaller-sample size case series¹⁰⁻¹⁴ or were from consultations limited to pediatric oncology clinical services.^{15,16} Across pediatric and adult settings, researchers have detailed a core set of recurring problematic clinical situations that lead to consultations, the pertinent ethical considerations commonly identified, and the variety of consult processes that exist across institutions.^{4-6,8,12,15,17}

In this article, we provide a descriptive report of pediatric ethics consultation conducted over a 6-year period at a children's hospital and large primary and specialty care network. In conducting this analysis, we had 2 principal aims. First and foremost, we sought to describe key contextual emotional, relational, and pragmatic attributes of specific pediatric ethics cases (such as miscommunication,^{15,16} conflict,^{12,17} and anger¹⁸) that arise from, cause, or complicate the ethical concerns or dilemmas that the consultation seeks to address. Identifying and addressing these contextual attributes, we believe, are fundamental tasks of effective ethics consultation. Empirical studies have, however, largely neglected to document the prevalence of these contextual attributes, and have not explored how these attributes may be associated with or influence other

aspects of consultations, such as the types of ethics problems encountered and the processes of engagement and dialogue by which the consultation unfolds.

Second, we aimed to provide additional empirical data about these other aspects of ethics consultations to motivate and inform the establishment of consensus definitions for future studies. Inconsistencies in the descriptive typologies used by different studies have been rightly criticized as limiting the ability to perform comparisons across studies or sites, and currently, no consensus typologies exist. Drawing on various typologies that have been published, we describe for each consultation the core problematic issue, the pertinent ethical considerations, and the engagement of stakeholders in the ethics consultation process, and we explore how these attributes were associated with the contextual emotional, relational and pragmatic aspects.

METHODS

The Children's Hospital of Philadelphia (CHOP) Institutional Review Board determined that this study did not represent human subject research.

Setting

CHOP comprises a 500-plus bed tertiary care hospital and a network of primary and specialty care providers serving patients from local, national, and international locations.

Ethics Consultation Service Structure and Process

Clinical ethics consultation at CHOP is provided by 4 members of the Ethics Consult Service (ECS), which reports to the hospital's ethics committee. Any patient, family member, or staff person can request an ethics consult (see Supplemental Fig 5). After initial discussion with the requestor, the primary ethics consultant (EC)

determines which other parties to engage initially. The primary EC reviews the medical record and involves one other ECS member as a secondary consultant. The final consultation process may range from a single conversation with the requester to clarify a piece of information or a policy, to multiple conversations with stakeholders, to a meeting with the clinical team, a separate meeting with the patient or patient's family, or to a combined meeting with the clinical team and the patient or the patient's family.

After the ethics consultation is complete, the EC communicates the ethics summary and any recommendations to those parties involved in the consultation. If a meeting occurred between the ECS and the patient or patient's family, or if the recommendations have implications for patient care, an ethics consultation note is entered into the patient's medical record.

Ethics Consultation Service Database

Ethics consults are recorded in a REDCap database by the primary EC. Consults are designated as either clinical (about a particular patient), policy (regarding a policy concern), or general (regarding a broader institutional issue). This analysis was limited to just clinical consults from 2013 to 2018.

Clinical consult records include patient demographics, information about the consult requestor(s), clinical information about the patient, the ethics question being asked, the consult process used, whether a consult note was entered into the medical record, and the ethical analysis and any recommendations provided.

Classification of Consultations Into Three Different Typologies

Ethicists have discussed the need for a typology for describing and classifying ethics consults.¹⁹⁻²² In 2013, when the ECS database was

TABLE 1 Contextual Attribute Categories, Definitions, and Case Examples

| Category | Definition | Case Example |
|-------------------------------|--|--|
| Simple lack of knowledge | Consult request is predicated on lack of knowledge about a fact or applicable policy. | Clinical team seeks to determine if mandatory reporting requirements regarding child abuse and neglect apply for a child under their care but who resides in a different jurisdiction. |
| Avoidance or miscommunication | Parties are either not communicating, communicating ineffectively, or are avoiding having any conversation at all. | Nurses are concerned that primary care team has not told the parents that there are no further curative treatments because of fear of starting a conflict. |
| Discord | Case has generated significant conflict or a general sense of discontent. | Medical team is distressed because the parents of an infant with complex congenital heart disease have not consented to proposed surgery out to fear of causing long-term suffering and worries about prognosis. Team is becoming worried that patient will become too ill to benefit from surgery if parents do not agree soon. |
| Entrenched positions | Parties hold conflicting opinions and are at a persistent impasse. | Parents unwilling to disclose diagnosis to 10-y-old child who requires lifelong treatment. Physician unwilling to provide treatment without disclosure. |
| Articulate disagreement | Parties each have an ethically tenable position, are able to communicate that position, but cannot come to agreement on a solution. | For a child with a fatal diagnosis, some medical team members believe that all further interventions are unwarranted and that current interventions should be de-escalated, whereas others believe that additional interventions may be warranted because they may allow the patient to live longer. |
| Genuine confusion | Consult requester is genuinely confused about the “right thing to do,” either because of complex clinical circumstances or because no good options exist, or because no one option appears better than the others. | Parents requesting to take their technology-dependent child home after lengthy admission, despite not having adequate home nursing to assure patient safety. Clinical team is unsure how to balance the potential harms with the family’s perceptions regarding the child’s best interests. |
| Thwarted agreement | Parties have come to an agreement but institutional or health care system–level issues are preventing the successful implementation of the plan. | Parents and medical team agree that patient with complex medical and behavioral health needs requires inpatient psychiatric treatment. No beds are available at inpatient psychiatric facility because of medical needs, while hospital environment is not safe for patient and staff. |

developed, the members of our ECS agreed on three aspects of each consult that warranted classification: core problematic issues, pertinent ethical considerations, and contextual attributes related to the consultation. Within each aspect, the primary EC determines which categories are most appropriate for classifying each consult.

We determined the categories of core problematic issues and of pertinent ethical considerations (Supplemental Tables 3 and 4) on the basis of a literature review and on problems identified in ECS records before 2013. For the contextual attributes categories, we had established before 2013 a provisional classification of various emotional, relational, or pragmatic underlying concerns that we had encountered and that, when

present, often influence the consultation process and need to be addressed (Table 1). Finally, we identified for each consult the consultative processes used, ascending from one-on-one discussion with requestor, to meeting with clinical team, to separate meetings with family and clinical team, to joint meeting with family and team, or another process entirely.

During the course of the consult process, the primary EC and the secondary EC discuss these aspects of the consult. When the consult has concluded, the primary EC determines and records the relevant categories for the consultation.

Analysis

Data were analyzed by using Stata 16.1 (Stata Corp, College Station, TX).

We first performed basic descriptive analysis of frequencies and percentages and plotted data in graphic format.

We then performed a 2-stage exploratory analysis to evaluate whether specific contextual attributes were associated with particular core problematic issues, pertinent ethics concerns, or cumulative consultation processes. Given the exploratory nature of this analysis, we used a *P* value of <.1 as our significance threshold. In stage 1, we performed an overall χ^2 test of each of the corresponding contingency tables, advancing to the next step if *P* < .1. In stage 2, to address the nonmutually exclusive nature of the contextual attributes and provide more detailed relationships between contextual attributes and both the core

TABLE 2 Demographic and Clinical Characteristics of 218 Patients Involved in 245 Clinical Ethics Consultations (*N* = 218)

| Characteristic | <i>n</i> (%) |
|-------------------------------------|--------------|
| Age | |
| Birth to 30 days | 19 (8.72) |
| 1–11 mo | 35 (16.06) |
| 1–4 y | 26 (11.93) |
| 5–9 y | 28 (12.84) |
| 10–14 y | 49 (22.48) |
| 15–17 y | 28 (12.84) |
| 18 y and older | 31 (14.22) |
| Missing | 2 (0.92) |
| Sex | |
| Male | 119 (54.59) |
| Female | 97 (44.50) |
| Missing | 2 (0.92) |
| Race | |
| White | 99 (45.41) |
| Black or African American | 57 (26.15) |
| Other ^a | 46 (20.64) |
| Asian | 6 (2.75) |
| American Indian or Alaska native | 1 (0.46) |
| Native Hawaiian or Pacific Islander | 1 (0.46) |
| Unknown or missing | 8 (3.63) |
| Ethnicity | |
| Not Hispanic or Latino | 189 (86.70) |
| Hispanic or Latino | 19 (8.72) |
| Unknown or missing | 10 (4.58) |
| Primary clinical service | |
| Critical care medicine | 41 (18.81) |
| Neonatology | 27 (12.39) |
| Adolescent medicine | 21 (9.63) |
| Cardiology | 21 (9.63) |
| General pediatrics | 17 (7.80) |
| Gastroenterology | 16 (7.34) |
| Oncology | 13 (5.96) |
| Metabolic disease | 6 (2.75) |
| Pulmonary medicine | 6 (2.75) |
| Endocrinology | 5 (2.29) |
| Neurology | 5 (2.29) |
| Rheumatology | 5 (2.29) |
| Nephrology | 4 (1.83) |
| Psychiatry or behavioral health | 4 (1.83) |
| Hematology | 3 (1.38) |
| Immunology | 3 (1.38) |
| Complex care | 3 (1.38) |
| General surgery | 2 (0.92) |
| Other | 15 (6.88) |
| Missing | 1 (0.46) |

^a “Other” category for race is as designated in the original data source.

problematic issues and the final culminating consultation processes, we performed stratified χ^2 analyses of each combination.

RESULTS

Between January 1, 2013, and December 31, 2018, the ECS performed 245 clinical ethics consultations. Of these, 27 consults

were “repeat” consultations, with the patient having been involved in at least 1 previous consult. Demographic and clinical characteristics of the 218 patients are presented in Table 2 (and Supplemental Table 5).

Core Problematic Issues

Of the 245 clinical consults, the most-commonly identified core

problematic issues (Fig 1, top panel) were intensity or limitation of treatment (38.8%; *n* = 95), treatment adherence or refusal (31%; *n* = 76), and decision-making, surrogate question, and capacity (27.8%; *n* = 68).

Pertinent Ethical Considerations

The most-frequently identified pertinent ethical consideration (Fig 1, bottom panel) in the clinical consults was the best interest standard (79.2%; *n* = 194), followed by benefits versus harms of treatment (51%; *n* = 125) and autonomy and decision-making authority and capacity (46.5%; *n* = 114).

Contextual Attributes

The most-frequently identified contextual issues related to these clinical ethics consults (Fig 2, top panel) were discord (43.3%; *n* = 106) and acknowledged dilemma (33.5%; *n* = 82), followed closely by articulate disagreement (29.8%; *n* = 73).

Final Cumulative Consultation Process

Most consults (78.0%; *n* = 191) began with a one-on-one conversation with the original requestor (the remainder often being a request to join a group discussion or meeting) and either concluded at that stage (34.3% of all consults; *n* = 84) or progressed to include 1 or more meetings with the clinical team (39.2%; *n* = 96), separate meetings with the clinical team and with the patient or family (9.4%; *n* = 23), or a combined meeting with the patient or family and the clinical team (8.2%; *n* = 20), with some consults (9.0%; *n* = 22) culminating in another distinct process, such as referral to General Counsel’s office, consultation with child protective services, or review by the ethics committee (Fig 2, bottom panel).

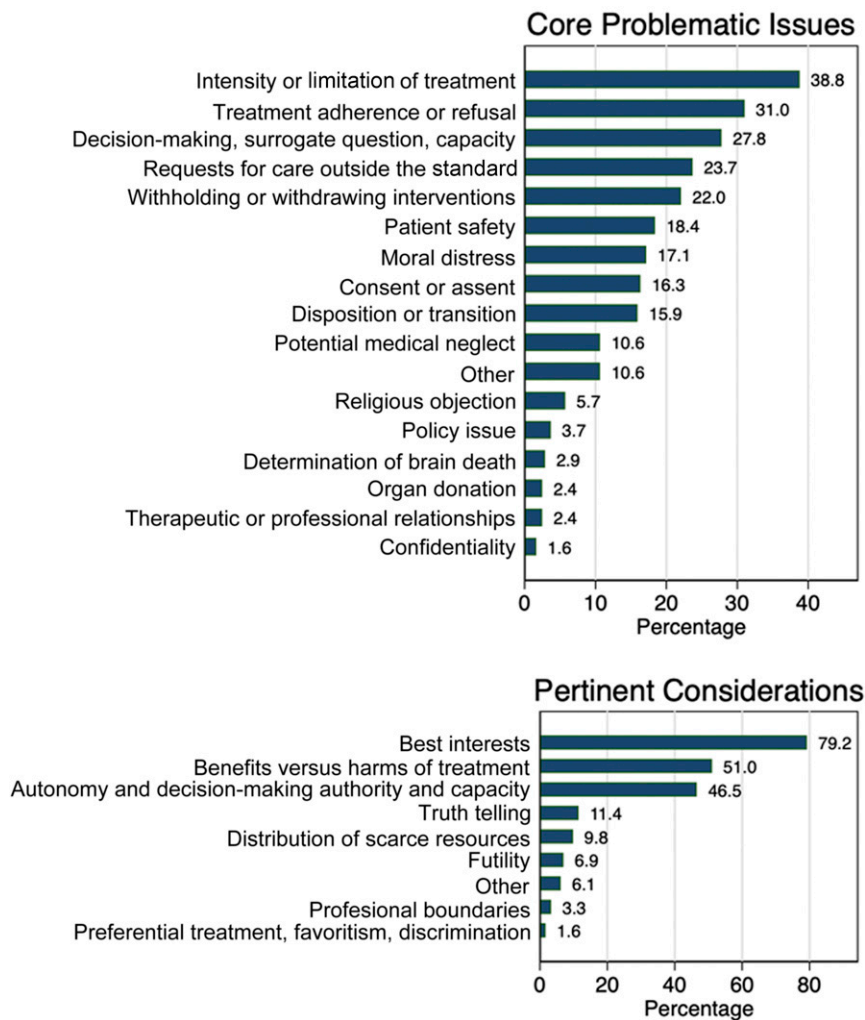


FIGURE 1 Prevalence of core problematic issues and pertinent ethical considerations identified in 245 clinical ethics consultations from 2013 to 2018. For core problematic issues, the “other” category included problematic issues such as innovative treatment, disability rights, and child abuse and protection. For pertinent ethical considerations, the “other” category included ethical considerations such as professional obligations, justice, and disparities.

Relationship Between Contextual Attributes and Core Problematic Issues

Exploratory analysis revealed that specific contextual attributes were associated with the core problematic issues that generated the consults (Fig 3; overall χ^2 test, $P = .01$). Discord was the most-commonly identified contextual attribute overall and was prevalent in consults stemming from all 7 core problematic issues, with an even higher prevalence when moral distress was noted (but not statistically significant). The prevalence of the

other contextual attributes ranged more broadly across the top 7 types of problems. For example, the contextual attribute acknowledged dilemma was least prevalent in cases of nonadherence (12.3%; $n = 19$) and most prevalent (25.3%; $n = 25$) for patient safety issues (χ^2 test for this contextual attribute, $P = .02$). Disagreement was most prevalent in cases of “requests outside the standard” (23.0%; $n = 28$) and least present in cases of “withholding or withdrawing treatment” (12.1%; $n = 11$) ($P = .02$). Avoidance was lowest for patient safety (5.1%; $n = 5$) and

highest for withholding or withdrawing treatment (16.5%; $n = 15$) ($P = .02$).

Relationship Between Contextual Attributes and Final Cumulative Consult Process

Although no relationship was noted to exist between the contextual attributes identified and the pertinent ethical considerations (overall χ^2 test, $P = .59$), a relationship was detected between the contextual attributes and the final consult process engaged in for each consult (Fig 4; overall χ^2 test, $P = .01$). Similar to the core problematic issues, the prevalence of each contextual attribute varied across the 5 cumulative consult processes. Lack of knowledge was most prevalent where the process was a one-on-one discussion with the requestor (18.3%; $n = 25$) and when the final consult process was other (22.0%; $n = 9$), most likely representing a referral to another hospital resource, but was never identified when the process was separate meetings with all parties involved in the consult (χ^2 test for this contextual attribute, $P = .001$). In contrast, the prevalence of thwarted agreement ranged from a low of 0% in cases in which the final consult process was other, to a high of 12.5% ($n = 22$) where the final process was a clinical team discussion ($P = .02$).

DISCUSSION

In this analysis of 245 pediatric ethics consultations conducted over a 6-year period in a large children’s hospital and regional clinical network, the clinical issues that most often led to an ethics consult were intensity or limitation of treatment, or treatment adherence and refusal of treatment. This set of ethically problematic clinical issues is consistent with findings from other studies.^{12,15,17} The annual rate of clinic ethics consultations, averaging 41 per year, is higher than what researchers in other pediatric studies

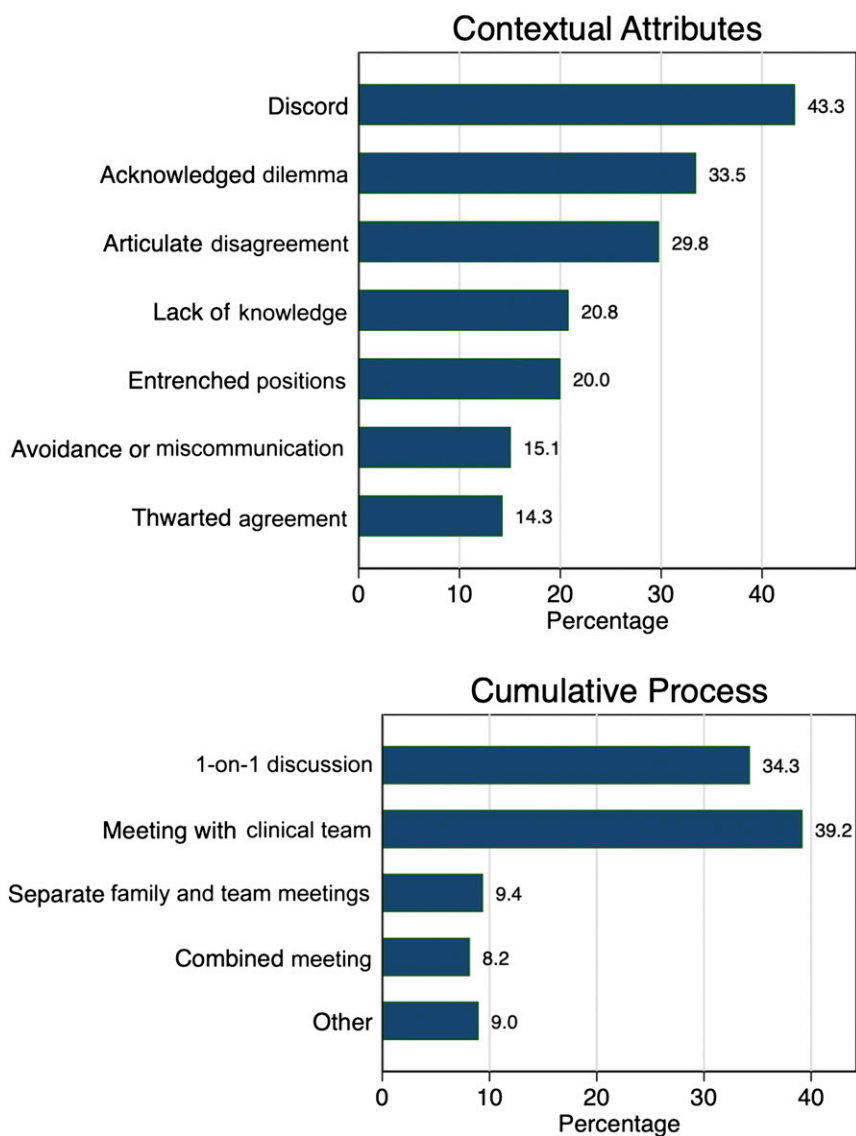


FIGURE 2 Prevalence of contextual attributes and final cumulative consult process identified in 245 clinical ethics consultations from 2013 to 2018. For cumulative process, the “other” category included processes such as referral to the General Counsel’s office, consultation with child protective services, or a full review by the ethics committee.

have reported.^{8,9} The consultative processes most-frequently used in our consults were either a one-on-one conversation with the requestor or a meeting with the clinical team, whereas fewer consults involved talking with the patient or family or a combined meeting of all parties. This practice pattern differs from what is sometimes strongly recommended, namely having patients or families involved in all consults.^{23–25} In addition, and novel

to this study, the emotional, relational, or pragmatic contextual attributes most-commonly encountered during ethics consultation included discord, acknowledged dilemmas, and articulate disagreement.

Clinical Issues Cited as Causes for Ethical Concerns

In our setting, the clinical issues that most often led to ethics consultation regarded the intensity or limitation of

treatment, or treatment adherence and refusal of treatment. Anecdotally, these requests were generated both when the clinical team believed that further treatment was unethical and the family wished to pursue continued aggressive treatment, and also when the family wished to limit treatment but the clinical team believed further aggressive treatment was indicated, although we do not have data regarding the frequency or ratio of these 2 scenarios. These disagreements may have led to the next most-cited problem, namely treatment adherence or refusal. Intertwined with both of these problems was the third most-commonly identified problem, which regarded concerns about decision-making capacity or questions about surrogate decision-making. As has been reported previously,²⁶ decision-making capacity is often first questioned within the context of disagreements between the patient or parent and the clinical team about the plan of care.

Underlying Contextual Attributes

Building on previous reports that have used the term contextual issues to report elements such as religious and cultural concerns²⁷ or communication conflict,¹⁵ we have expanded the set of contextual attributes to include additional relational and emotional factors such as discord, articulate disagreement, and avoidance or miscommunication, as well as pragmatic issues such as lack of knowledge and thwarted agreement, both of which are often highly context dependent. We found that these contextual attributes were significantly associated with specific core problematic issues as well as the cumulative consult process. This finding suggests that a given core problem can occur in situations with quite different sets of contextual attributes, which in turn might necessitate a different consultative process.

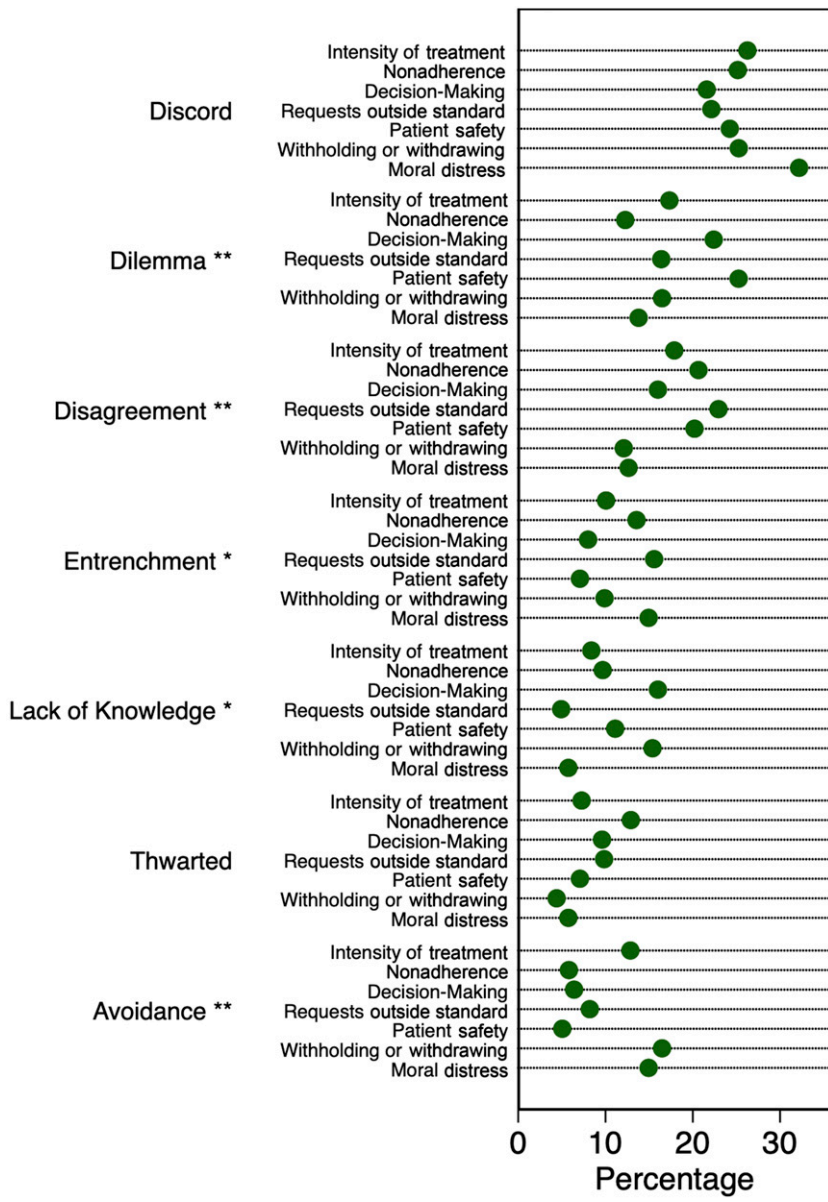


FIGURE 3 Prevalence of contextual attributes across top 7 core problematic issues in 245 clinical ethics consultations from 2013 to 2018. For each contextual attribute × core problem, *** $P < .01$, ** $P < .05$, * $P < .1$.

With our combined ethics consultation experience, we have developed a two-pronged approach to assessing each consult. One prong conforms to the traditional role of the EC: identify and clarify the ethical dilemma, discern the values differences among the parties involved, and apply ethical principles or concepts to the dilemma to provide an analysis and recommendations. The other prong,

which has not traditionally been clearly articulated as being within the responsibility of the EC,²⁸ involves assessing the emotional, relational and pragmatic attributes that exist alongside (and that at times overwhelm) the clinical and ethical aspects of the consult. This second assessment can provide valuable insight regarding how best to approach each consult.

For example, for a consult in which the parties feel confused about which clinical option is the “right” one, but without any elements of anger, distrust or discord, the standard ethical analysis approach may be sufficient. By contrast, in a case in which the parties are engaged in an angry argument, or, in the absence of anger, in which multiple parties are feeling discord and sadness in response to an ethically challenging clinical situation, without first addressing the emotions and relationships, facilitating a dialogue focused only on ethical considerations may be ineffective. A case that is suffused with anger and entrenched positions may require shuttle diplomacy, with multiple separate meetings with the parties involved,²⁹ or a mediation approach that attempts to define some common ground.³⁰ In a case infused with a general sense of discord or dismay, the best approach may be a large meeting including the patient or parent, in which all parties can share their feelings and coping strategies, along with the underlying ethical analysis and justification. In our experience, attending to these contextual attributes is vital if the consultant is to help the patient, family, and clinical team navigate these ethically complex encounters.

Adaptive Approach to Consultation Process and Family Participation

Given the variability in the contextual attributes of consults, our ECS uses an adaptive approach to the consultation process, with each consult conducted in the manner deemed most appropriate by the primary and secondary consultants. This approach enables a timely and efficient service and may in part account for the relatively large annual number of ethics consultations performed.

Of note, our ECS infrequently involves patients and their family members in the ethics consultation process. Most of our consults are requested by

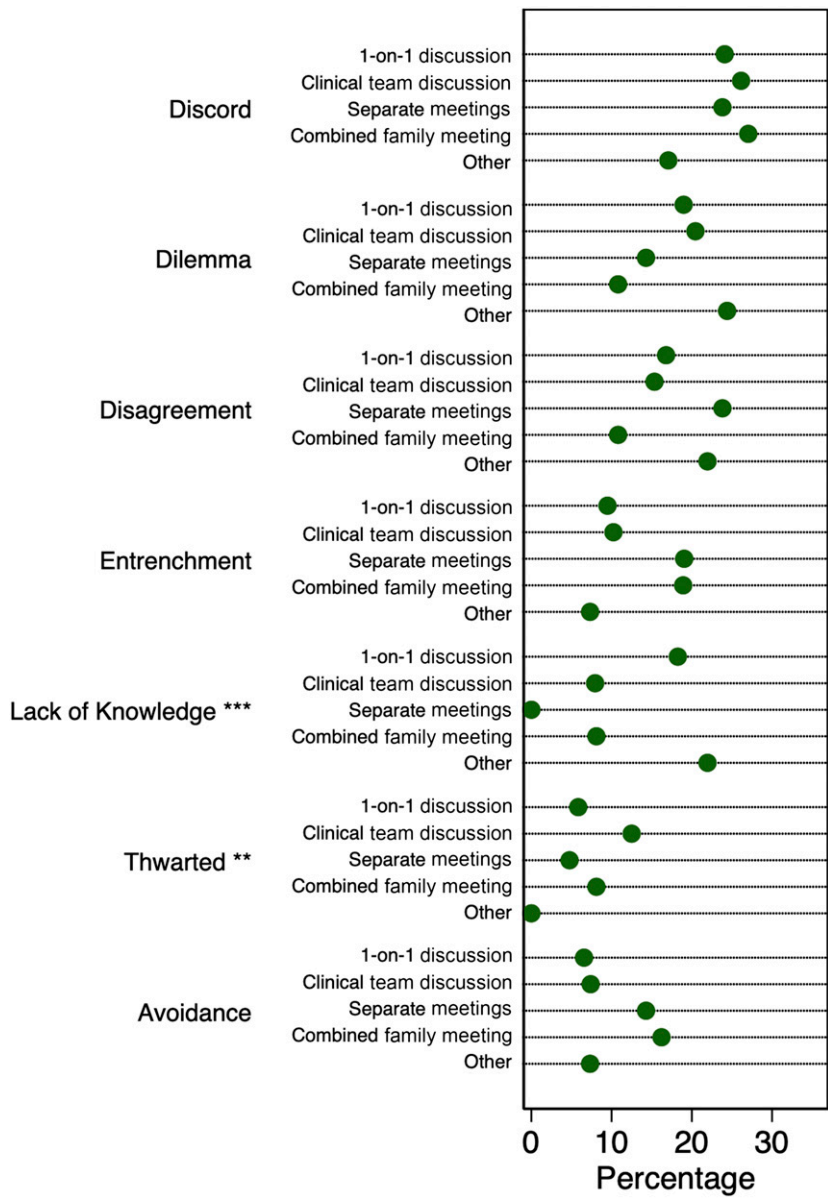


FIGURE 4
Prevalence of contextual attributes across the 5 cumulative consult processes in 245 clinical ethics consultations from 2013 to 2018. For each contextual attribute × ultimate process, *** $P < .01$, ** $P < .05$, * $P < .1$.

clinical staff, and often confusion or conflict within the clinical team about the “right thing to do,” clinically as well as ethically, is the primary problem. The ensuing ethics consultation focuses on helping clinical team members to understand the ethical implications of treatment options, clarify divergent views about these options, and dialogue in a manner that reaches consensus about the plan of care.

In consults that include disagreement between the patient or family and the clinical team, clarifying for the clinical team ethical elements of the case (such as parental discretion in decision-making or a competent adult patient’s right to refuse recommended treatment) often resolves the issue. Furthermore, coaching clinical staff to communicate more effectively with patients and family members rather than relying

on outside intervention facilitates subsequently more collaborative ongoing relationships between patients and families and clinical teams.

Importantly, circumstances clearly exist in which patients and parents should be included in the ethics consultation process: for example, when the patient or parent has initiated the consult, when the patient’s or parent’s values require further exploration, or when the ethical rationale behind a particular treatment recommendation or refusal needs to be explored.

Limitations

Four limitations of our study warrant discussion. First, as with most studies of ethics consultation services, findings from this single organizational setting study should not be generalized, but comparisons to other published reports can be illuminating. Second, the individual EC categorized each consult regarding core problematic issues, pertinent ethical considerations, and contextual attributes after discussing the case with colleagues, but no formal assessment of interrater agreement has been conducted. Third, as yet no consensus exists regarding a classification typology of ethics consults; we believe that the 3 separable “dimensions” of clinical consults (problematic issues, pertinent ethical considerations, and contextual attributes) that we used offers advantages, in terms of analysis and potential understanding, compared with a single set of categories.

Fourth, and finally, we have no outcome data to evaluate our ethics consultation practices. Indeed, we believe that defining and then measuring ethics consult outcomes are major challenges to advancing the field. What are sometimes cited as consult outcomes are more precisely descriptions of clinical care processes

(such as continuation or cessation of life-supporting technologies) or patient outcomes (such as survival to discharge or death). These process and patient outcomes may or may not be attributable to the ethics consult, and whether they are reliable signs of a high quality or successful consult is unclear. More apt would be measures of whether participants believed the process to be fair and

the recommendations clear and justified.

CONCLUSIONS

Pediatric ethics consultations address a broad array of problematic issues that in turn raise a variety of pertinent ethical considerations, all the while occurring in a context that should be accounted for when

settling on the most appropriate process for conducting the ethics consultation.

ABBREVIATIONS

CHOP: Children's Hospital of Philadelphia
EC: ethics consultant
ECS: Ethics Consult Service

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