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Content Review of Pediatric Ethics Consultations at a Cancer Center

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Abstract

Background/Objectives: Ethical challenges in pediatric oncology arise at every stage of illness. However, there is sparse data on the content of and reason for ethics consultations in the field. We sought to evaluate the content and characteristics of ethics consultations in pediatric patients at a cancer center.

Design/Methods: We retrospectively identified ethics consultations performed for patients diagnosed with cancer at 21 years of age who were treated in the Department of Pediatrics from 2007–2017. Using an established coding schema, two independent reviewers analyzed the content of ethics consultation notes and identified core ethical issues and relevant contextual issues. Demographic, clinical, and consultation-specific data were also collected.

Results: 35 consultations were performed for 32 unique patients. The most commonly identified ethical issues were obligation to provide non-beneficial treatment (29%) and resuscitation preferences (26%). Communication conflicts were the most commonly identified contextual issue (40%). There were two themes that emerged repeatedly but were not a part of the original coding schema: four consultations (11%) involved physicians questioning their obligation to provide potentially toxic treatment in the setting of poor patient/parent compliance, and two consultations

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(6%) related to complex risk/benefit analysis in the setting of an invasive procedure with uncertain benefit.

Conclusions: Pediatric ethics consultations are infrequent at this specialty cancer hospital. Ethical issues focused on treatment and end-of-life care and included a diversity of communication conflicts.

Keywords

Ethics; Pediatrics; Ethics Consultations; Oncology

Introduction

Ethics committees are present in most hospitals in the United States (US)¹ but the prevalence of clinical ethics consultations is variable, ranging from 0.16–3%.^{2–4} Several factors influence the rate of ethics consultations in US hospitals: consultation model (mandatory versus elective);² hospital setting (medical/surgical floor versus intensive care unit [ICU]);^{2,5} and patient population (adult versus pediatric).⁶

In adult medicine, ethical issues most frequently involve the dyad of medical provider and either the autonomous patient or the surrogate/healthcare agent when the patient lacks capacity. Large reviews identify the main concerns pertaining to ethics consultations for adult patients as appropriateness of treatment, resuscitation status, withdrawal of life-sustaining treatment, and patient decision-making capacity.^{5,7–10}

Pediatric ethics, however, is unique in that there are three key stakeholders: patient, family, and health care team. With few exceptions, pediatric patients lack competence and the dynamics of medical decision-making are inherently more complex.^{11,12} In pediatrics, clinicians must balance a fiduciary responsibility to protect the child's best interests with the autonomy of the family.¹³

Few articles in the medical literature provide details on the content of and reason for pediatric ethics consultations; prior reviews have focused on young infants, non-malignant diagnoses, and the ICU setting.^{14–17} Ethical issues are reported most frequently in medical situations involving extremely premature neonates, children with congenital problems or life-limiting syndromes, and withdrawal of life-sustaining treatment after traumatic events requiring ICU admission.^{14–17}

The ethical issues that arise in pediatric oncology are distinct, but data for consultations in the field are sparse. To date, the most comprehensive evaluation of the issues prompting ethics consultations in pediatric oncology comes from St. Jude's Children's Research Hospital.¹³ The authors identify a variety of ethical issues prompting consultation, the most frequent being fiduciary responsibility, delivery of care with unclear benefit, and prognosis/goals of care. This is the only review of ethics consultations in a specialized oncology hospital to date, and the authors encourage further work on the topic. Our aim is to add a second institution's experience to the medical literature.

The objectives of this study were to evaluate the content, characteristics, patterns, and outcomes of ethics consultations in pediatric oncology at a single comprehensive tertiary cancer center using the Nilson coding schema.¹⁸

Methods

Setting

Memorial Sloan Kettering (MSK) is a 434-bed academic tertiary care National Cancer Institute (NCI)-designated specialty cancer hospital in New York City. The Department of Pediatrics specializes in the treatment of children, teenagers, and young adults with cancer and blood disorders, and the pediatric cancer program is the largest of its kind in the United States with approximately 1400 pediatric inpatient admissions and 23,000 pediatric outpatient visits in the center per year.

The ethics committee at MSK is a multidisciplinary committee with 40 current members. Ethics consultations are conducted by a subgroup of ethics committee members with training in clinical ethics. The consultants include physicians specializing in critical care, palliative care, pediatrics, neurology, and psychiatry, nurses, and social workers.

Ethics consultations can be requested in the inpatient or outpatient setting by clinical staff or family members. When an ethics consultation is requested, the consultant first discusses the case with the requestor(s) to understand the issues prompting the consultation. The medical chart is reviewed and clinical and family stakeholders are identified and interviewed as appropriate. The primary role of the ethics consultant is to attempt value-neutral mediation and to enhance communication. In rare situations based on New York state law, the outcome of the ethics consultation is binding¹⁹. But more typically, the ethics consultant will recommend the involvement of other consultation services like palliative care, identify relevant hospital policy or state law, bring forward the voice of the patient, and/or facilitate family or provider meetings. A formal consultation note is documented in the medical record.

Data Collection

We used a pre-existing centralized ethics consultation database to retrospectively identify all patients with cancer diagnosed at < 21 years who were treated by the pediatric service at MSK and had an ethics consultation performed between January 2008–December 2017.

We collected the following demographic and clinical data at the time of the ethics consultation: age, gender, race, preferred language, religious affiliation, primary admitting service, hospital location (outpatient, inpatient floor, ICU), and use of life-sustaining interventions, including mechanical ventilation, vasopressors, continuous renal replacement therapy or hemodialysis, if applicable. Disease-related variables included cancer or disease type (central nervous system, leukemia/lymphoma, neuroblastoma, sarcoma, or bone marrow failure syndrome), interval since cancer diagnosis, and disease-related therapies (i.e., chemotherapy, radiation therapy, surgery, or image-guided interventions such as catheter drainage of fluid collections and effusions) administered within 30 days prior to or

during patient encounter. Also, we reviewed hospital admission and hospital discharge dates, in-hospital mortality, and six-month mortality.

Ethics consultation-specific data collected included date of ethics consultation, role of the individual requesting the ethics consultation (physician, nurse practitioner, registered nurse, patient representative, patient, agent or surrogate), and whether an interpreter was used. Determination of the patient's ability to participate in discussion of care was based on the assessment of the medical team at the time of the consultation. In most states, a child under the age of 18 is not legally competent to make healthcare-related decisions (with the exception of an emancipated minor); however, a mature child can express preferences and values, and in almost all jurisdictions, it would be unusual to go against the wishes of a school-age or teenage child of normal intelligence. Therefore, we documented whether the patient was able to participate in discussion of care, and among these patients, whether the patient was legally competent. We documented the relationship of the parent or surrogate decision-maker and resuscitation status before consultation and within seven days after consultation.

Two side-by-side reviewers analyzed the ethics consultation note content and reported the reason for consultation using an established coding schema for ethics consultation.¹⁸ We chose to use a tool that had been previously utilized by ethics researchers at our institution^{20,21}, thereby building upon prior work and enabling comparison of ethical issues between the adult and pediatric populations. The reviewers assessed core ethical issues based on the narrative portion of the consultant's note. Disagreements between the two side-by-side reviewers were mediated by a third independent reviewer. We also identified important contextual issues as established by Nilson et al¹⁸, including cultural/ethnic/religious issues, communication conflicts, perception of patient or family in denial, physician attitude toward treatment, and quality of life. We documented the involvement of palliative care, chaplaincy, social work, psychiatry, legal services, and child protective services before and after ethics consultation.

Data Analysis

Descriptive statistics included absolute number, percentages, mean with standard deviation, and median with interquartile range when data were skewed.

The study was approved by the MSK Institutional Review Board/Privacy Board.

Results

During the 10-year study period, 35 consultations were performed for 32 unique patients (mean, 3.5/year). Most consultations (n=31, 89%) occurred in the inpatient setting, where there are 36 pediatric beds and approximately 1400 annual admissions.

Demographic and Clinical Data

Demographic data, primary language, religious affiliation, and cancer type are shown in Table 1. All patients (100%) had advanced-stage, metastatic, recurrent, or refractory malignancy. Prior to hospital admission or outpatient visit, 31% (n=10) of patients had been

diagnosed with cancer in the past year, 53% (n=17) in the past one to five years, and 16% (n=5) had been living with cancer for five years or more. The majority of ethics consultations (83%) were called for patients who had oncologic therapies administered within 30 days prior to or during the consultation period. Median hospital length of stay for the 28 inpatients was 42 days (interquartile range [IQR]: 20–90 days) and 54% of these inpatients had life-sustaining therapy during admission. Twenty of the 28 inpatients died; six-month mortality was 69% (Table 2).

Ethics Consultation Data

Ethics consultations were performed by nine consultants. Eighty-three percent of consultations (n=29) were requested by a physician, with the remaining requests made by a nurse practitioner, registered nurse, or patient representative. No requests were made by patients or family members.

At the time of ethics consultation, 94% of patients had one or both parents as the decision-makers; 9% of patients had a DNR order in place; and 74% lacked the ability to participate in the consultation due to clinical status (e.g. sedation, altered mental status). After the consultation, an additional 20% of patients had DNR orders placed (Table 3).

Prior to ethics consultation, all but one case involved at least one of the following resources: palliative care, psychiatry, social work, chaplaincy, legal, and child protective services. After ethics consultation, there were a total of nine requests for additional consultations, including social work (n=3), chaplaincy (n=2), palliative care (n=1), psychiatry (n=1), legal (n=1), and child protective services (n=1).

Content Analysis

There was an average of 1.5 ethical issues per case (range of 1–4). The most frequently identified primary ethical issues driving consultation were obligation to provide non-beneficial treatment (n=7, 20%), goals of care (n=5, 14%), resuscitation preferences (n=5, 14%), and parental decision-making (n=5, 14%). Parental decision-making was identified as an ethical issue when there was disagreement between two parents and when the treatment team was concerned that one parent was not acting in the best interest of the child. Table 4 summarizes the frequency of all ethical issues represented for the consultations.

Communication conflicts were the most commonly identified contextual issue (n=14, 40%), followed by physician attitude toward treatment (n=8, 23%) and cultural/ethnic/religious preferences (n=6, 17%) (Table 5).

There were two themes that emerged repeatedly but were not a part of the *a priori* coding schema used in this study. Four consultations (11%) were called by physicians questioning their obligation to provide potentially toxic treatment in the setting of poor patient/parent compliance or inadequate social support. In each of these cases, intensive chemotherapy or stem cell transplantation with curative intent was being offered to the patient but concerns were raised that potential toxicities, including neutropenia, hemolysis, and life-threatening infections, could outweigh any potential benefit due to a history of poor compliance with medical appointments and prophylactic antibiotic regimens. Two consultations (6%)

involved complex risk/benefit analysis in the setting of an invasive surgical procedure with uncertain benefit that had potential to improve quality of life in patients with end-stage disease.

Analysis in Older Patients

We included patients diagnosed with cancer between 18–21 years of age who were treated by a pediatric oncologist; these patients had cancers that typically affect children. Among this age group, parents were intimately involved in decisions about treatment with the exception of one case. None of the patients were married; their parents were next of kin and surrogate decision-makers when the patient did not have decision-making capacity. Obligation to provide non-beneficial care was a predominant theme, as it was in the younger age groups. The issues of patient autonomy and obligation to provide treatment for a patient with poor social support or inconsistent compliance were more frequently observed in this age group compared with younger age groups.

Discussion

Pediatric ethics consultation was rarely requested at our institution, which is in keeping with prior literature reports. Researchers have offered a multitude of reasons for the low incidence of ethics consultations in pediatrics. They have hypothesized that clinicians are unaware that ethics consultations are available or do not know how to request them,²² that medical teams feel they can address ethical issues without help,²³ that clinicians perceive a lack of qualifications among ethics consultants,⁶ or that residents and nurses worry about repercussions from the attending physician.²⁴ Carter et al²⁵ propose that ethical dilemmas may also be addressed in different forums outside the realm of the traditional ethics consultation. At MSK, we have a number of supportive services in place, and we agree that these individuals, including survivorship clinic physicians, social workers, psychologists, and palliative care team members, likely play a role in addressing ethical issues and preempt the need for a formal ethics consultation.

In our cohort, no ethics consultation requests were made by family members. It is possible that families may not know the service exists, and/or may not know how to request an ethics consultation without the assistance of the medical team.¹³ Furthermore, we hypothesize that families do not call ethics consultations because they do not identify an ethical dilemma. For example, a family's request for likely non-beneficial treatment may be understood by the family as a demonstration of advocacy for the patient, rather than an ethically challenging situation for the treating physician. Families may also hesitate to call an ethics consultation because they worry they will offend the team caring for their child.

The work by Johnson et al reports more than half of the ethics consultations occurring in the outpatient setting and only one-fifth occurring in the ICU, with a low number of consultations concerning the limitation of life-sustaining treatment.¹³ They attribute the infrequency of ICU consultations to clear plans of care developed in the outpatient setting, as well as other ways of addressing inpatient conflicts, including interdisciplinary team conferences. In contrast, 89% of our institution's ethics consultations took place in the inpatient setting, 72% of which took place in the ICU. Although our institution is a

comprehensive cancer center providing care for individuals along the cancer continuum, ethics consultations were called only for patients with recurrent, refractory, or metastatic disease, and the majority of ethical issues related to provision of non-beneficial treatment at the end of life and DNR status. There were no ethics consultations at diagnosis or during survivorship, even though these times are rife with ethical concerns such as truth-telling, confidentiality, genetic testing, clinical trials, long-term effects of toxic treatments, pain management, and fertility concerns. We propose the following explanations for the contrasting ethical issues found at the two institutions.

First, Johnson et al attribute the frequency of outpatient ethics consultations to easy access to ethics consultation and integration of outpatient ethics consultation with primary clinic appointments. Our institution's ethics committee and consultation service started in the inpatient setting, and teams request consultations about primarily inpatient issues. It may be perceived as more challenging to coordinate an outpatient ethics consultation because there is minimal precedent for integration of appointments. More streamlined access to outpatient ethics consultations by pediatric oncologists may increase the frequency of consultations at the time of diagnosis, disclosure, and survivorship, since these stages generally occur in the outpatient setting.

Second, as previously discussed, we have a robust array of supportive services that may address the ethical issues that are not the focus of ethics consultations at MSK. Survivorship physicians and genetic counselors work primarily in the outpatient setting and are trained to navigate ethical challenges like disclosure, fertility, and genetic testing for future children. The inpatient palliative care team not only helps to facilitate discussions about goals of care, but also provides a high level of expertise in pain management. Additionally, there have been efforts to support collaboration among community Jehovah's Witness representatives, the medical team, and the institutional legal counsel and address issues related to transfusion consent at the time of initial presentation to MSK.

Third, MSK is an NCI-designated Comprehensive Cancer Center with more than 80 ongoing clinical trials in pediatrics alone. Many families transfer care to MSK after exhausting treatment options at out-of-state or international institutions, thereby generating a bias toward patients who have late-stage or refractory disease and whose families are seeking a miracle.

Finally, we believe that clinicians may fail to recognize ethical dilemmas beyond the confines of treatment-related decision-making and goals of care at the end of life. Further education is needed to help medical teams identify these ethical issues and utilize the resource of ethics consultation. The Ethics Committee has recently implemented educational initiatives to address this need, such as an annual Ethics Committee Retreat and an ethics seminar series for pediatric providers.

Researchers have criticized the use of nonstandard, institution-specific classification of reasons for ethics consultation, noting the need for a common list that can be used across studies.^{26,27} In response, we chose to use the Nilson coding schema, which was created based on data collected from ethics consultations at multiple institutions serving a diverse

patient population.¹⁸ Our institution has utilized this coding schema in prior research,^{20,21,28} enabling comparison across studies. Still, we found that the Nilson coding schema was limited in its ability to capture some of the unique issues that arose in our patient population. We identified two additional themes in our review that were not in the *a priori* coding schema. First, there were four cases in which clinicians expressed concern about offering potentially toxic treatment to patients or parents who had demonstrated non-adherence or poor follow-up in the past. This moral dilemma is well-described in the solid organ transplant literature, where prior evidence of patient/parent compliance and strong social support are explicit criteria for selecting candidates.^{29,30} In contrast, the oncology literature describes adherence challenges during chemotherapy,^{31,32} but does not guide clinicians as to whether anticipated adherence problems should factor into the decision to administer or withhold chemotherapy. Similarly, the deleterious outcomes of poor adherence have been described in pediatric bone marrow transplant recipients,³³ and while psychosocial factors including adherence may be considered in bone marrow transplant candidates, there is not a universally standard approach.³⁴

Also not included in the coding schema was the idea of complex risk/benefit analysis as applied to an invasive procedure. For example, an ethics consultation was called to help determine whether it was ethical to place a ventriculoperitoneal shunt to improve quality of life in a terminal patient, knowing that the risk of mortality during surgery was high and the benefit was likely incremental. While it is common to balance risks and benefits in the context of a patient's goals of care, at times, this calculus is particularly complex. Ethics consultants may offer additional decision-making support in these situations and we suspect that this use of the resource occurs more often than has been captured in this case series. It may be helpful in future ethics consultation research to assess how often consultants are called upon to assist in complex risk-benefit analysis.

The most commonly identified contextual issue was communication conflict. The ethics surrounding communication between families and medical teams have been well examined, albeit mostly in adults.³⁵⁻³⁷ Our results reinforce prior work noting that communication conflicts do not exist just between families and medical teams;³⁸ rather, intra-family and intra-staff conflicts were prevalent as well and represented half of the communication conflicts that we identified. Intra-family communication conflicts at our institution involved parents who disagreed about treatment course or resuscitation status for their child and their inability to communicate a unified decision. Intra-staff communication conflicts related to moral distress experienced by primary nurses carrying out orders placed by physicians and their discomfort communicating this distress due to a barrier of perceived hierarchy. Understanding the diversity of communication conflicts is critical in order to better recognize and address these issues in the future.

Our study has several limitations. First, this is a single-center study at a large cancer hospital, and the results are not immediately generalizable to other settings, particularly smaller, less specialized institutions. Second, we had a small sample size owing to the rarity of pediatric ethics consultations at our institution, and our review found that the consultations focused only on treatment and end-of-life issues. Third, our study did not collect data on socioeconomic status, education level, or health literacy, which are

potentially important contributors in any ethics consultation. Additionally, although we used an established coding schema for ethical issues and contextual themes, the coding process has several limitations. Johnson et al at used a novel classification scheme, which was critiqued for its failure to use a common list of standardized reasons for ethics consultation that would enable comparison.^{26,27} This criticism was our rationale for selecting the Nilson coding schema. However, the Nilson coding schema was developed for the adult population and did not focus on cancer patients; the downside of our approach is that we sacrificed goodness of fit of the coding schema to the data we aimed to characterize. Furthermore, the coding process is inherently limited by coder subjectivity, and there is the temptation to force the data to fit into established categories. We identified two ethical issues that were not included in the coding schema, but there may be others. Finally, our interpretation of communication conflict as a contextual issue was broad and included both the concepts of principled disagreement and miscommunication. These are separate issues and to describe them as communication conflicts may be an oversimplification.

Conclusions

Ethics consultations are infrequent in pediatric oncology at MSK. The most commonly identified ethical issues were obligation to provide non-beneficial treatment and resuscitation status; there were a diversity of communication conflicts. Requests for ethics consultation at our institution currently focus on treatment and end-of-life issues; education is needed for both parents/guardians and clinicians to increase awareness of ethical issues related to other elements of cancer care, including diagnosis, treatment, survivorship, and research. Future longitudinal work is required to determine how the content of and reason for ethics consultation in pediatric oncology will change with ongoing therapeutic advances.

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Abbreviation Key:

US	United States
MSK	Memorial Sloan Kettering
ICU	Intensive care unit
DNR	Do not resuscitate
CPR	Cardiopulmonary resuscitation
NCI	National Cancer Institute

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TABLE 1

Patients' demographic data, race, primary language, religious affiliation, and cancer type

Characteristics	n (%)
Total patients	32
Age	
< 1 year	1 (3)
1 year to < 4 years	2 (6)
4 years to < 12 years	12 (38)
12 years to < 18 years	8 (25)
18 years	9 (28)
Male	21 (66)
Race	
White	16 (50)
Black	12 (38)
Asian	2 (6)
Other	2 (6)
Primary language	
English	26 (81)
Other	6 (19)
Religion	
Christian	13 (41)
Catholic	7 (22)
Jewish	7 (22)
Muslim	4 (12)
Jehovah's Witness	1 (3)
Disease type	
Hematologic	12 (38)
Central nervous system	11 (34)
Sarcoma	6 (19)
Neuroblastoma	3 (9)

TABLE 2

Clinical and outcome data

Variables	n (%), Median (IQR)
Hospital location	
Floor	18 (52) ^a
ICU	13 (37)
Outpatient	4 (11)
Oncologic therapy within 30 days prior to or during patient encounter	29 (83) ^a
Use of life sustaining therapy	15 (54) ^b
Outcome data	
LOS among hospitalized patients, days	42 (20–90)
In-hospital mortality	20 (71) ^b
Six-month mortality	22 (69) ^c

^aDenominator of 35 ethics consultations^bDenominator of 28 unique inpatients^cDenominator of 32 unique patients

TABLE 3

Ethics consultation data

Variable	n (%)
Consult requested by	
Physician	29 (83)
Other hospital staff	6 (17)
Family	0 (0)
Patient participation	
Patient participation possible	9 (26)
Decision-making capacity present	6 (17)
Patient participation not possible	26 (74)
Relationship of decision-maker to patient	
Parent(s)	33 (94)
Both	17 (48)
Mother only	13 (37)
Father only	3 (9)
Other	2 (6)
DNR order	
Before consultation	3 (9)
After consultation	10 (29)

TABLE 4

Ethical issues

Ethical Issue	n	%*
Obligation to provide non beneficial treatment	10	29
DNR	9	26
Parental decision making	8	23
Goals of care	7	20
Patient autonomy	5	14
Informed consent	3	9
Withdrawal/withholding of life sustaining therapy	3	9
Treatment refusal	2	6
Resource allocation	1	3
Truth telling	1	3
Advance directives	0	0
Confidentiality	0	0
Pain management	0	0
Other	6	17
Obligation to provide potentially toxic treatment with concern for inconsistent compliance	4	11
Principle of proportionality	2	6

* Total exceeds 100% because most cases had > 1 ethical issue; mean = 1.5 ethical issues/case

TABLE 5

Contextual issues

Contextual Issue	n	%*
Communication Conflict	14	40
Staff-Family	7	20
Intra-Family	5	14
Intra-Staff	2	6
Physician attitude toward treatment	8	23
Cultural/Ethnic/Religious	6	17
Perception of patient or family in denial	3	9
Quality of life	1	3
Other	9	26
Long-term follow-up during potentially toxic treatment	4	11
High risk procedure	2	6
Language/communication barrier	1	3
Non-paternity	1	3
Parent with impaired cognition	1	3

* Total exceeds 100% because most cases had > 1 contextual issue

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