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Ethics Consultation in Pediatrics: Long-Term Experience from a Pediatric Oncology Center

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Abstract

There is little information about the content of ethics consultations (EC) in pediatrics. We sought to describe the reasons for consultation and ethical principles addressed during EC in pediatrics through retrospective review and directed content analysis of EC records (2000–2011) at St. Jude Children's Research Hospital. Patient-based EC were highly complex and often involved evaluation of parental decision making, particularly consideration of the risks and benefits of a proposed medical intervention, and the physician's fiduciary responsibility to the patient. Non-patient consultations provided guidance in the development of institutional policies that would broadly affect patients and families. This is one of the few existing reviews of the content of pediatric EC and indicates the distribution of ethical issues and reasons for moral distress are different than with adults. Pediatric EC often facilitates complex decision-making among multiple stakeholders and further prospective research is needed on the role of ethics consultation in pediatrics.

Keywords

Ethics Consultation; Decision Making; Conflict Resolution; Autonomy; Risk-Benefit Assessment; Pediatric Hospital

Introduction

Ethics consultations are provided by a hospital ethics committee (HEC), consult team, or individual bioethicist. The frequency of ethics consults (EC) varies widely in U.S. hospitals. Ninety percent report fewer than 25 annually (Fox et al. 2007), and most pediatric centers report 1–10 per year (Kesselheim et al. 2010). Satisfaction with EC is reported to be high (>70%) among clinical staff (Duval et al. 2004; Orr et al. 1996; Yen and Schneiderman 1999).

The concerns that prompt EC requests are well described in adult and combined adult-pediatric centers. In adults, EC are dominated by end-of-life issues, capacity assessments, and identification of surrogate decision makers (Duval et al. 2001, 2004; La Puma et al. 1988, 1992; Shuman et al. 2013; Swetz et al. 2007; Tapper et al. 2010). In contrast, little is known about the ethical issues that predominate in pediatric settings and the concerns that prompt consultation requests.

A search of the literature identified two previous reviews of pediatric EC in the United States and two amongst European populations. Two reviews found limitation of treatment (withdrawing or withholding) or conflict about treatment to be dominant issues, but the patients involved in both studies were most likely to be an infant < 1 year of age and the majority of patients were located in an intensive care unit (ICU) (Orr and Perkin 1994, Streuli et al. 2014). The review by Opel focuses on organizational issues surrounding consultation rather than the broader issues that trigger EC requests (Opel et al. 2009). The retrospective review by Streuli focuses more on a proposed model for ethical decision-making during consultation, identified as the Zurich clinical ethics structure (Streuli et al. 2014). The article by Ramsauer and Frewer also focuses on the process of consultations at their center and does not provide an organized review of consultation content (Ramsauer and Frewer, 2009).

EC in pediatrics are unique because medical decisions involve a triad of stakeholders—the patient, family, and health care professionals—all working toward the patient’s best interest (Lyren and Ford 2007). Parents are allowed wide discretion in medical decision making and provide informed permission, yet as children mature they formulate opinions that are increasingly given weight, depending on the child’s age, maturity, and illness experience. Clinicians have the fiduciary responsibility to protect the child’s best interests while also respecting familial autonomy. Given the different spectrum of illnesses, the decisional concerns unique to pediatrics, and the frequent reluctance of parents and clinicians to forgo treatment that offers even slight hope of impact on the disease (Bluebond-Langner et al. 2007; Mack et al. 2007; Maurer et al. 2010), we believe it would be informative to characterize the concerns that prompt requests for consultation and the content of EC in pediatric centers. EC have evolved over time; however, recent reviews of the content of EC in pediatrics do not seem to exist in the literature.

Given the sparseness of literature on pediatric EC, particularly in children with cancer, our primary objective was to examine 11-years of pediatric EC and provide data on the relevant ethical issues encountered at a pediatric academic medical center. Our secondary objective was to compare our findings to what has been reported in the existing literature. We reviewed all EC at St. Jude from 2000 (the HEC first year) through December 2011.

Institutional Overview

St. Jude Children’s Research Hospital (St. Jude), a 78-bed pediatric hospital located in Memphis, TN specializes in the treatment of children with life-threatening disorders, primarily cancer. St. Jude is a national and international referral center for children with cancer as well as a local referral center for children with human immunodeficiency virus

infection and blood disorders such as sickle cell disease, hemophilia, and other primary immunodeficiency disorders. Children who reside within the hospital catchment area (approximately 200 miles around Memphis, TN) or who present at a St. Jude affiliate site (Baton Rouge (LA), Huntsville (AL), Johnson City (TN), Peoria (IL), Shreveport (LA), and Springfield (MO)) are eligible for treatment. Patients outside of these areas are referred by a physician, diagnosed with a disease currently under study, and eligible for a research protocol. St. Jude also operates an international outreach program with 20 international partner sites in 14 countries. St. Jude does not have an emergency room or neonatal intensive care unit and does not admit children with diseases outside these diagnostic groups; however research conducted at St. Jude covers a broader scope of health issues than the disease treated as a primary diagnosis (<http://www.stjude.org/SJFile/Community-Health-Needs-Assessment-6-28-13.pdf>). St. Jude physicians provide hematology-oncology and infectious disease consultation at Le Bonheur Children's Hospital, also located in Memphis, TN. Approximately 7,800 active patients are seen yearly at St. Jude, many of whom are treated on a continuing outpatient basis and often as part of ongoing research programs (www.stjude.org, searched September 2013). Approximately 65% of oncology patients are treated on therapeutic research studies, which are consistent with other pediatric academic centers treating children with cancer (<http://www.childrensoncologygroup.org/index.php/what-is-a-clinical-trial>, accessed April 2014).

The HEC was founded in May 2000 after an ad hoc committee identified that St. Jude was unique among pediatric hospitals in not having a standing HEC. Today, the HEC is a multi-disciplinary committee with 21 members, including three members with advanced training in bioethics. The majority of members on the committee have received on-the-job training including required reading and mentoring with an experienced ethicist. The committee meets monthly and is comprised of 3 sub-committees focusing on: (1) clinical consultation, (2) ethics education, and (3) institutional policy review and development with a focus on ethical issues and concerns.

Our HEC uses the small team (2–5) model of consultation and is similar in structure and function to what has been reported by other pediatric centers (Kesselheim et al. 2010). Clinical consultations are supervised by at least 1 clinical ethicist. Our ethics consultants are increasingly making direct contact with family stakeholders, when appropriate, to solicit their direct perspective rather than rely on reports from clinical staff. When a consult request is received we briefly discuss the case with the requestor(s) to clarify the concerns that led to the request. We review the chart for the purpose of understanding the medical and psychosocial features of the patient and family. If the query involves other clinical staff we will contact them in order to solicit their view of the conflict. Understanding the case and the perspective of clinical stakeholders is helpful to focus the discussion when we interview the family. The ethics consultants will coordinate an interdisciplinary team meeting following the family interview to further assess staff perceptions with the aim of identifying possible solutions to the conflict at hand. It is in this setting that stakeholders (clinicians, ancillary staff, administration, etc.) come together with the ethics consult team to discuss recommendations and develop an action plan. A formal written consultation report follows and is now placed in the medical record. Generally the role of the consultant is to make recommendations, however when the relationship between staff and family has been

contentious, consultants have offered to act as a neutral mediator. In present practice, the clinical ethics consultant will continue to follow the case and remain available to address ongoing ethical concerns. Broader requests for policy consultations have been conducted by ad-hoc working groups comprised of members from all sub-committees. Clinical ethics consults are discussed and reviewed with the entire HEC for the purpose of committee growth and education.

Methods

This is an Institutional Review Board approved retrospective review of the EC records. Copies of all available EC records ($n = 53$) were obtained from the centralized, electronic records of the HEC. All formal reports were included; records of informal “curbside” requests for consultation were excluded. Early consults (2000–2002; $n = 8$) were recorded in the HEC meeting minutes. Four of these early consultations were excluded from content analysis because the minutes lacked sufficient descriptive information for adequate coding. These four consultations lacked some or all of the following: family characteristics, problems or reasons for conflict, family and or staff preferences, ethical principles addressed, or consult outcome/recommendations. When available, descriptive demographic data was obtained from each record. Consultations were reviewed for involvement with external services such as chaplaincy, palliative care, legal, or child protective services.

Qualitative Data Analysis

Directed content analysis (Hsieh & Shannon 2005) was used to identify the ethical issues that prompted requests for EC. This method uses predefined themes (domains) drawn from existing data and provides a more structured approach than conventional content analysis by applying an existing framework in a new context for the purpose of validation and extension (Burla et al. 2008; MacQueen et al. 1998; Opel et al. 2009).

The coding lexicon was generated by identifying the broad ethical themes cited in previous reviews of the content of EC and adding representative pediatric issues. The published literature demonstrates heterogeneity in the grouping of ethical issues with some authors listing individual ethical dilemmas (capacity, DNR status) and others reporting higher-level concepts (Goals of Care). To accommodate for this variability we identified six broad ethical domains: Level (Quality) of Care, Decision-making, Interpersonal Conflict, Religious/Cultural Issues, Justice, and Professional Responsibility. More specific ethical issues (sub-domains) were assigned to each domain. For example, the domain “Decision Making” contains parental decision-making as one sub-domain and child preference as another sub-domain. Complex subdomains had multiple codes (Table 1).

Within each consult, every phrase in the consultation report was analyzed for ethical meaning, and where appropriate, a code from the lexicon designating that ethical meaning was applied. A specific code was applied once per consult, even if it was reflected in multiple phrases. When a phrase was felt to overlap multiple codes, both would be coded as present in the consultation.

The consult records were coded separately by two primary investigators (LMJ, JNB) and discussed to resolve differences. The consults were then coded by two additional investigators (KTO, CLC) and reviewed with the primary investigator (LMJ) to generate the final (consensus) set of codes. Triggering issues for consultation and secondary issues (identified during the consult) were recorded. Simple inter-rater reliability for the initial and second reviews was 95% after the first 20% of consults were reviewed, reflecting the learning curve as reviewers (physician, doctoral-level ethicist) completed study-specific training and gained familiarity with the lexicon. Descriptive statistics were generated from the data. The Spearman's rank correlation coefficient was used to assess whether there was a monotonic relationship between the annual number of consults and time. The Wilcoxon rank-sum test was used to compare the total number of codes per consult between patient and non-patient consultations as well as to look for differences in mean number of consultations before and after initiation of the palliative care service (PCS).

Results

Fifty-three formal consults occurred during the study period (mean, 4.41/year) with 4 excluded (see methods), leaving 49 for analysis. The annual number of consults varied and did not increase over time (Spearman's rank correlation coefficient ($r = 0.004$, $p=0.991$)). Most EC involved a specific patient (83%); one patient had two unrelated EC. Demographic data for the 43 patients involved in 44 EC is provided in Table 2. Represented in beds, clinical consultations averaged 4.2 consults per 100 beds over the study period. The majority of consultations were requested by physicians, sometimes after consultation with hospital administration (Table 2). Hospital administration may become involved to ensure that the institution is exhausting all options toward reaching resolution with a family before pursuing unilateral action to resolve the conflict. This is particularly true if there are concerns about a pursuing a court order or transferring medical care to another provider and permanently discharging the patient.

Nine EC did not involve a patient. One of these (1.8%) involved a hospital blood donor whom a nurse recognized from a confidential outside meeting as having disclosed a previous history of intravenous drug use which he was not disclosing during screenings for blood donation. The remaining eight were policy-based EC, six of which provided guidance when institutional policy was lacking or inadequate (Table 3). These consults had a mean of 2 domains per consult and were limited to the domains of Decision-making, Justice, and Professional Responsibility. The Wilcoxon rank-sum test was used to compare the total number of codes per consult between patient and non-patient consultations. Patient consultations were more complex than non-patient consultations, with a mean of 6.2 (SD 2.4) versus 3.6 (SD 0.9) codes per consult, respectively ($p=0.002$). Please note that although the result is statistically significant, the small sample size of nine non-patient consultations may not be representative of the true population.

Table 1 shows the distribution of codes; each includes an illustrative quotation from the consult report that is representative of an ethical code from the lexicon. Fiduciary responsibility was the most frequent reason (27%) for requesting a patient-based EC. Other common reasons for requesting consultation were delivery of care when the benefit was

unclear (22%) and prognosis/goals of care (20%). The subdomains most frequently present throughout patient consults were beneficence/non-maleficence (13%) and fiduciary responsibility (12%); with 73% of patient consults containing at least one of these subdomains. Table 4 compares the results of our study with others published in the literature.

Religious issues were identified in 35% of patient EC. When an EC involved religion-based refusal of medical treatment, it was consistently the consult trigger (10% of patient-focused EC). An additional 15% of patient-focused EC involved religious beliefs contrary to medical evidence. Chaplaincy services participated in 100% of consults with religious concerns and in 75% of consults overall (Table 2).

Our PCS was formally established institution-wide in March 2008. Thirteen patient EC arose after the initiation of the PCS. There was no difference found in the number of consultations per year before and after the implementation of palliative care services, with a mean (SD) of 3.7 (3.2) versus 3.3 (2.1), respectively ($p=0.992$). Of the 13 post PCS consultations, one concerned EOL issues and was followed by the PCS; another two cases involved decision-making around a patient with a high-risk diagnosis but the PCS was not involved. Legal representatives from the hospital participated in 22.5% of patient consults, most of which (67%) had occurred since 2010. A small proportion of EC (7.5%) involved child protective services.

Most patient-based EC reports (55%) recommended a care conference or interdisciplinary team meeting. Unfortunately, records do not exist regarding details of meetings that followed the consultation report or the exact role (if any) of the ethics consultant during these meetings. A family care conference was not indicated, when the EC concerned conflicts among clinicians over what treatment alternatives should be offered when the prognosis was uncertain. In these patient-focused EC, conflict and moral distress occurred among members of the team and was sufficiently distressing that assistance from ethics was requested. Twenty percent of EC reports included suggestions for institutional policy development or clarification.

The competing best interests of a patient requiring hematopoietic stem cell transplantation (HSCT) and of a sibling stem-cell donor candidate who was a minor occurred in 7.5% of patient consults. The ethical question was always “Are the risks to the sibling acceptable, given the potential benefit to the patient?” These consults (2005–2007) occurred before the hiring of a donor advocate and publication of the American Academy of Pediatrics (AAP) policy on sibling HSCT donation (AAP Committee on Bioethics 2010).

Discussion

This review indicates that EC in pediatric oncology are of high complexity and single patient consultations address a multitude of ethical issues across a broad variety of domains. Our experience appears distinct from what has been published in the literature to date.

In this study, limitation of life-sustaining medical treatment (LSTs), conflict within families, and decisional capacity were less common reasons for EC than previously reported (Table 4)

(Duval et al. 2001; La Puma et al. 1988 and 1992; Moeller et al. 2012; Opel et al. 2009; Orr and Perkin 1994; Shuman et al. 2007; Swetz et al. 2007; Tapper et al. 2010). Parents are considered the de facto decision-makers for their children; therefore, distress about a patient's decisional capacity, or about which family member is the decision maker of record, are less likely to occur in pediatrics when the patient is a minor child. Parents facing decisions on the limitation of LSTs rank their child's quality of life, chance of getting better, and degree of discomfort as very important in the decision-making process (Maurer et al. 2010; Meyer et al. 2002). Clinicians in the intensive care unit often become sources of support for parents facing decisions on limitation of LSTs and parents often find greater agreement with staff members than with their own family (Meyer et al. 2002). In pediatric critical care, where the decision-making nexus is limited to parental caregivers who are receiving both emotional support and medical information from a specialized community of providers, conflicts over goals of care may be minimized and shared-decision making optimized, thus reducing the likelihood of conflict and need for EC. Alternatively, pediatric providers may be willing to allow parents more time to reach a decision on the limitation of LST before requesting an EC. Further research is necessary to clarify the aforementioned differences.

Religious concerns (refusal of care, belief in religious healing, and demands for medically inappropriate care in expectation of a miracle) appear more common in this pediatric review (8%–21%) when compared to adult EC (Table 4). EC are a useful response to religious-based refusal of treatment for a minor. Education targeting these refusals as well as other reasons for parental refusal may be appropriate and should not be limited to members of the HEC, but be made widely available to all clinical staff involved in patient care. The participation of chaplaincy services in the EC may facilitate better understanding of the value commitments underlying religious refusals. We encourage HEC to assist with the development of clear institutional policies about parental refusal of treatment that are consistent with state law and AAP recommendations.

Consultation requests were often prompted by distress arising from disagreement about a treatment plan or from inadequate clinician-family communication about the rationale for the plan. Our findings demonstrate a high degree of fiduciary responsibility among pediatric subspecialists, who experience moral distress when their obligation to promote a child's best interest is constrained by parental action (or inaction), or perceived to be causing a direct risk of harm to the child (or to the child's interests). This finding is consistent with the high frequency with which beneficence/non-maleficence was identified as an EC trigger. Clinicians frequently consulted for assistance (1) when deliberating if potentially burdensome treatments (among various alternatives) were truly in the patient's interest or (2) when deciding how to clarify the goals of care with a family when the prognosis was poor. In these cases, EC fostered communication and facilitated decision making. Although decision-making, professional responsibility and quality of life represent different ethical domains, they were frequently found in coexistence in the consultation reports and are reflective of a more general protective paternalism. There appears to be a strong professional duty to advocate for care goals that align most with the clinician's personal sense of what would be in the child's best interest. This was an important factor when clinicians questioned parents' rights to make a decision for their child without clinician involvement,

particularly when their decision appeared to threaten the clinician's execution of this professional duty.

In evaluating parental decision-making, it is important for providers to understand that parents may weigh issues that differ from those considered by the clinician, or may give issues different weight. For example, parents may consciously (or sub-consciously) consider the competing interests of their other children or the long-term interests (versus current interests) of the ill child. Clinicians should discuss the parents' rationale with them and consider competing interests that may constrain decision-making. In our experience, use of a patient advocate may be helpful. The patient advocate is an impartial third party whose role is to be an objective listener, counselor, and advocate. In our research setting, patient advocates can observe the consent discussion to assure accuracy of the presentation, verify apparent understanding of the parent and child (when applicable), and ensure voluntary participation in the study.

A large proportion of our consultations were provided in the outpatient setting. We believe clinicians may have appreciated the importance of thoughtful advance guidance when navigating decision-making and care coordination, prior to hospital admission, in chronically ill children for which there is no clear "best" treatment choice. The organizational structure of St. Jude provides ready access to EC for outpatients, which should be encouraged at all pediatric centers. Consultation requests are accessible through computerized order entry, an internal intranet link, or via page through an online call schedule with all the aforementioned methods accessible in both the outpatient clinics and inpatient units. We have established an easy to remember email (ethics@stjude.org) that physician and non-physician providers can use to request formal consultation or informal advice. Families are made aware of ethics consultation primarily through direct contact (when consultant attends bedside rounds or when facilitated by clinical staff) and when the ethics committee has been described in parental newsletters. It is a committee goal to further increase visibility with families over the next year.

At St. Jude the patient's primary clinic can be considered their "medical home." We meet with families in their primary clinic at times adjacent to their other appointments using a private consultation room. Working with clinic schedulers, we are able to formally "book" appointment times with families for outpatient consultation. When an interdisciplinary team meeting or family care conference is needed, we often work with a member of the nursing and/or social work staff in the clinic to coordinate a convenient meeting time and location. Outpatient consultation may resolve differences sufficiently to prevent a crisis prior to hospital admission. In the inpatient setting conflict and distress may be exacerbated by involvement of staff unfamiliar with the patient, family, and circumstances, thereby increasing the level of emotion, and impeding negotiation between medical staff and families even more.

Our results differ from those reported previously in that a minority of consultations occurred in the ICU and we coded a lower frequency of consults concerning the limitation of life-sustaining technologies. The lower frequency may reflect the long-term nature of patients' care and the trust that develops between the primary team and family. At St. Jude, conflicts

in the inpatient setting are often resolved through interdisciplinary team meetings and family conferences without a need to request assistance from the ethics consultant; further, outpatient EC are likely to have clarified the care plan in advance of admission.

Due to the retrospective nature of this review, we cannot accurately report the percentage of cases where treatment decisions changed as a result of the EC. In cases where this is available, treatment decisions both have and have not changed as the result of consultation. The impact appears to be influenced by the nature of the question at hand and contextual features of the case.

Some case examples may provide some clarity on the impact of consultation on case outcomes. One case involved a 16 year-old with a renal tumor requiring radical nephrectomy. The family identified as Jehovah's Witness and refused to sign consent for blood products. Although the likelihood to need transfusion was low, this caused distress among the medical team; particularly with the surgeon who stated that he "would be unable, in good conscience, to allow a pediatric surgical patient to bleed out," should a life-threatening bleed develop. The ethics consultants worked with legal, administration, and the family to design a consent form in which the patient and mother only had to "acknowledge" that blood products would be given in the event of life-threatening emergency. A court order was avoided and the medical team was able to maintain a positive, non-adversarial relationship with the family. In another example the medical team struggled with the right course of action in a three year old child who was referred to our institution after undergoing surgical resection of an abdominal mass (neuroblastoma) at an outside medical center. During that surgery the child experienced cardio-pulmonary arrest and anoxic brain injury with severe neurologic damage. It was not yet possible to quantify if the child would be in a persistent vegetative state (PVS) or have a more meaningful neurologic recovery. The medical team requested assistance thinking through possible treatment options: chemotherapy with curative intent, life-prolonging treatment without curative intent, or treatment directed towards comfort and relief of suffering without anti-tumor properties. If curative intent was pursued, the team wonder if the child should be treated on a research protocol given the poor overall survival with current standard of care treatments for high risk neuroblastoma. Ethics consultation helped the medical team evaluate the options and have meaningful conversations with the family valuing the parent's perceptions of their child's best interests. The child ultimately underwent an abbreviated chemotherapy regimen (shortened by parental request), radiation, and Accutane therapy. The patient has severe neurocognitive impairments as a result of the anoxic brain injury, but is not in a PVS. The child was alive seven plus years after diagnosis with no active evidence of cancer at that time. Further information is not available as the family relocated and transferred to another institution.

Nearly 41% of oncology patients referred to St. Jude in 2012 resided outside of the catchment area or affiliate geographic areas, which may suggest a selection-bias toward families who value the pursuit of cure despite the burden of referral to a non-local pediatric hospital. St. Jude also has approximately 80 patients enrolled on Phase I research studies annually, many of whom are referred in nationally. Phase I studies in oncology are not cure-directed studies (frequently dose-finding/escalation studies) which offer a low prospect of

direct benefit. Previous research in informed consent has shown the vast majority of families approached for a phase I will decide to enroll (Miller et al. 2013). Despite a population of families who potentially place a high value on hope and the pursuit of cure, consultations regarding the limitation of life-sustaining technologies remained quite low.

Pediatric oncologists are reported to be less likely than other subspecialists to identify care as overly burdensome (Solomon et al. 2005). If close, longitudinal relationships are combined with a sense of fiduciary responsibility to maintain the child's life, could pediatric oncologists lean toward a "try everything" approach (despite the burdens it entails and the lack of evidence of efficacy)? Such a perspective might impair their ability to recognize ethical principles concerning the goals of care and to place appropriate limitations on treatment as a child approaches the end of life in the ICU (Christakis and Lamont 2000). Prospective examination of the way in which the level of the patient-clinician relationship affects a clinician's ability to weigh risk-benefit decisions and identify ethical issues is warranted. A study of the effect of scheduled ethics rounds in high acuity pediatric care units focused on prognosis, goal setting, and decision making would also be informative.

Conflicts about treatment are reportedly more common when children have been previously healthy compared to when they had been chronically ill the family or care team may be reluctant to "give up" on a recently healthy child for whom there are no good treatment options (Orr and Perkin 1994). In contrast, when the child has been chronically ill, formal or informal advance care planning may have occurred (Weiner et al. 2012), and the family and care team have had time to prepare emotionally and rationally for the child's possible death. When children become suddenly ill, it may be helpful to involve the family's pediatrician, whose advice may be accepted more readily by parents.

Palliative care consultation may reduce conflict (and the need for an EC) by introducing discussions about goals of care, facilitating decision-making, and coordinating advance care planning. One limitation of this retrospective review is the inability to identify cases where palliative care consultation prevented an EC due to involvement in a child's care. We believe that the palliative care team's experience with shared-decision making and facilitation of communication are a form of preventive ethics that likely prevented additional consultations. Further prospective research on the impact of palliative care services on conflict resolution, decision-making, and preventing formal ethics consultation is warranted.

Barriers to Ethics Consultation

Any individual, including parents or anonymous individuals, may request an EC at our institution, yet there were no parental requests and nurses infrequently did so. In the case of one nurse requestor, internal committee correspondence indicated that she had experienced backlash from the attending physician and regretted her EC request. This perception has been validated by HEC members housed in nursing and during informal conversation with nurses across the institution. Similar experiences are likely everywhere: 25% of nurses surveyed at a large Midwestern hospital reported repercussions (primarily expression of anger) from the attending physician after requesting an EC (Gordon et al. 2006). Multiple consultations were requested by a small number of physicians at our institution, while most did not request consultation. DuVal and colleagues (DuVal et al. 2004) noted that

consultations are more often requested by physicians experienced in and knowledgeable about ethical issues or who practiced critical care. Institutional changes are needed to increase physician comfort with the prospect of requesting and participating in EC. The most important change needed is to prevent the perception of attending physicians that a consult request reflects negatively on their decision-making; in our experience, the underlying problem has more often been poor communication than inappropriate treatment. Perceptions can be altered by reframing consultation as a resource. HEC and palliative care providers can collaborate to provide integrated education about the ethical dilemmas of decision-making for critically ill children. We are working with the institutional family advisory council and nursing to increase awareness among families about the availability of EC. Further study is needed to specify the main barriers to consult requests and the misperceptions underlying the unreceptive attitude of many physicians toward EC requests. Education and cultural change can then be targeted to these barriers.

Limitations

An important limitation of this review is the unique nature of St. Jude, a specialized pediatric research hospital focused on a subset of childhood diseases. The institution has no neonatal intensive care unit and does not provide emergency services. Unlike other pediatric centers, such as that reviewed previously (Opel et al. 2009; Orr and Perkin 1994), we do not address major perinatal and congenital disorders; therefore, our study contained relatively few patients less than 1 year old ($n=1$, 2.4%). Furthermore, as our patients receive care that often spans years, most patient care is outpatient with fewer patients in intensive care. We were unable to retrospectively identify informal requests for advice and the discussions that may have followed; this information may be made available by prospective recording of discussions. Despite these limitations many of the ethical issues encountered in our institution have also been addressed in policy statements from the AAP Committee on Bioethics (AAP.org). While these results are limited to a specialty area of pediatrics we believe this is an important starting point for future discussion on the role of clinical ethics consultation in pediatrics and encourage further research on the topic in all areas where children receive medical care.

Conclusion

Cases prompting EC requests at our pediatric center were highly complex, and the specific concerns differed from those previously reported in adult populations. To increase acceptance of ethics-facilitated discussions and consultations, studies are needed to further clarify the barriers to EC requests. In the interim, pediatric ethics committees can increase awareness through targeted education about frequently encountered ethical issues and the HEC's role as a resource. Suggested venues include ethics rounds, clinical rounds, and invited speakers; case-based presentations provide opportunities to educate about specific ethical dilemmas. Clinical ethicist consultants can engage in preventive ethics by attending rounds in selected areas to educate team members, foster communication, answer questions, and facilitate decision-making. In our experience these activities are helpful in promoting acceptance of EC. Clear identification of HEC members raises awareness of the HEC among staff and may encourage formal or informal consultation requests. HEC should advocate for

organized, systemic ethical practices at the organizational level for the purpose of fostering an ethical environment and culture that becomes integrated from administration to all areas of the institution. Given the potential for consultants to mediate and arbitrate, institutions may consider formal mediation training to further enhance the skill set of their clinical ethics consultants.

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Coding lexicon with distribution of primary reason for consult request and all identified ethical issues in patient and non-patient consultations. De-identified phrases have been pulled from the consult records to demonstrate application of the ethical issues during coding.

Table 1

Coding Lexicon: (Domain ^a , Subdomain ^b , Code ^c)	Primary Reason(s) for Consult n (%)	Times Code Appeared n (%)	Patient Consults for Whom Code Appears n (%)	Times Code Appeared n (%)	Patient Consults for Whom Code Appears n (%)	Non-patient Consults Expressing Code n (%)	Sample Quotation
	All	Patient	Patient	Patient	Non-Patient	Non-Patient	
	Total=49	n = 245	Total=40	n = 32	Total=9		
LEVEL (QUALITY) OF CARE^a	21 (43)	77 (31)	36 (90)	0	0	0	
Goals of Care^{b,c}	10 (20)	21 (9)	21 (53)	0	0	0	<ul style="list-style-type: none"> “...is it to have as many good days left as possible or is it to avoid prolonging the dying process?”
Prognosis^b (Disease Survival Unclear, Benefit of Proposed Therapy Unclear, Futility)^c	11 (22)	22 (9)	16 (40)	0	0	0	<ul style="list-style-type: none"> “No therapy has been identified as unequivocally curative.” “The fellow was quite direct in explaining the risks and improbability of success ... that in this case the transplant team was treading where no one had gone before.” “Legal counsel clarified that physicians were not bound to provide interventions they judge medically inappropriate and burdensome to patients who are actively and irreversibly dying.”
End of Life^b (Withholding or Withdrawing life-sustaining therapy, Resuscitation Issues)^c	9 (18)	18 (7)	11 (28)	0	0	0	<ul style="list-style-type: none"> “Given that the child has continued to live > 3 weeks, would it be ethically appropriate to continue to withhold hydration?” “What ethical responsibility does the hospital have toward a patient/family who refuses to agree to a DNAR when the patient’s condition is terminal and irreversible?”
Palliative Care^{b,c}	4 (8)	16 (7)	16 (40)	0	0	0	<ul style="list-style-type: none"> “His pain is described as excruciating ... Multiple attempts to control the child’s pain were unsuccessful.” (Regarding initiation of palliative sedation therapy)
DECISION MAKING^a	24 (49)	76 (31)	36 (90)	9 (28)	7 (78)		

Coding Lexicon: (Domain ^a , Subdomain ^b , Code ^c)	Primary Reason(s) for Consult n (%)	Times Code Appeared n (%)		Patient Consults for Whom Code Appears n (%)		Times Code Appeared (%)		Sample Quotation
		All	Patient	Patient	Non-Patient	Patient	Non-Patient	
		All Total=49	n = 245	Total=40	n = 32	Total=9		
Parent (or Guardian) Decision^b (Identification/ Validity of Decision Maker, Capacity/ Competency of Decision Maker) ^c	0	6 (2)	4 (10)	0	0	0	<ul style="list-style-type: none"> • “The mother is involved and appears to have full custody.” • “The mother is having great difficulty ... she appears to detach and remove herself from the need to make decisions on her child’s behalf as a way to cope.” 	
Benevolent & Non-Maleficence^b (Best Interests, Competing Best Interests (siblings, staff) ^c	11 (22)	31 (13)	29 (73)	4 (13)	4 (44)	<ul style="list-style-type: none"> • “In transplant cases, the availability of follow-up care is a relevant consideration in judging the proportionality of benefits and harms.” • “Are the risks for the sibling greater than the potential benefit for the patient?” (Regarding minor sibling as HSCT donor) 		
Child Preference or Assent^{b,c}	1 (2)	8 (3)	8 (20)	2 (6)	2 (22)	<ul style="list-style-type: none"> • “[The patient] said she wanted “everything” including dialysis, etc.... Her parents were torn between their desire to honor their daughter’s wishes and not seeing her suffer needlessly.” 		
Advance Care Planning (Advance Directive / Health Care Proxy^{b,c})	1 (2)	5 (2)	5 (13)	0	0	<ul style="list-style-type: none"> • “The mother has expressed a desire to have a DNaR on the chart and the patient (age 20) does not want to participate directly in this decision making process but clearly continues to participate indirectly by refusing to accept her mother’s DNaR plans.” 		
Constrained Decision Making^b (Decisional Capacity / Competence, Threatened Autonomy, Decision-Making for Competent Patients, Incompetent Patient without Surrogate) ^c	5 (10)	11 (5)	9 (23)	0	0	<ul style="list-style-type: none"> • “Staff expressed concern that given the patient’s mental status (borderline dull), she might not have sufficient understanding of her prognosis, the recommended course of treatment, and the effects of treatment...” • “During a meeting with the local Jehovah’s Witnesses liaison the parents appeared unwilling to accept major blood components that Witnesses generally forgo ... later the parents told staff that he [liaison] was “not their minister” and showed some willingness to act independently of his religious counsel.” 		

Coding Lexicon: (Domain ^a , Subdomain ^b , Code ^c)	Primary Reason(s) for Consult n (%)		Times Code Appeared n (%)		Patient Consults for Whom Code Appeared n (%)		Times Code Appeared n (%)		Non-patient Consulting Code n (%)		Sample Quotation
	All	Patient	Patient	Non-Patient	Patient	Non-Patient	Patient	Non-Patient	Non-Patient	Total=9	
	Total=49	n = 245	Total=40	n = 32	Total=9						
Adherence^b (Nonadherence, Refusal of Recommended Treatment, Demands for Treatment) ^c	10 (20)	15 (6)	12 (30)	3 (9)	2 (22)						<ul style="list-style-type: none"> • “The patient has demonstrated non-compliance (not taking 6-MP for most of his ALL therapy) ... Is it ethical to go forward with BMT if, in our opinion, he will be noncompliant with BMT?” • “Patient bargains for which aspects of care he will accept and refuses others. This is an incredibly stressful situation for all staff involved in his care.” • “They continue to demand chemotherapy options, which the primary team considers potentially risky and harmful...”
INTERPERSONAL CONFLICT^a	4 (8)	20 (8)	18 (3)	0	0						
Family Conflict^b (Between medical staff & patient/family, Between Patient & Surrogate) ^c	2 (4)	14 (6)	13 (33)	0	0						<ul style="list-style-type: none"> • “The nurses have experienced considerable distress from both their perception that the child’s pain is not adequately controlled and the perception that the mother treats them with disrespect and condescension.” • “The patient’s mother is a very negative person and acts like her daughter is a burden. Relationship is very strained.”
Staff or Professional Conflict^{b,c}	2 (4)	6 (2)	6 (15)	0	0						<ul style="list-style-type: none"> • “Concerns on the part of some member(s) of the clinical service about providing less than optimal clinical management, described by one team member as a ‘departure from the standard of care.’”
RELIGIOUS / CULTURAL^a	5 (10)	14 (6)	14 (35)	0	0						
Religious Refusal of Care (ex-Jehovah’s Witness)^{b,c}	4 (8)	4 (2)	4 (10)	0	0						
Religious Beliefs in Conflict with Medical Science^{b,c}	0	6 (2)	6 (15)	0	0						<ul style="list-style-type: none"> • “The parents believed that further medical treatment was unnecessary, since they believed that God had healed the child ... the parents took the child’s improved appearance as evidence of God’s work.”

Coding Lexicon: (Domain ^a , Subdomain ^b , Code ^c)	Primary Reason(s) for Consult n (%)		Times Code Appeared n (%)		Patient Consults for Whom Code Appears n (%)		Times Code Appeared n (%)		Patient Consults for Whom Code Appears n (%)		Non-patient Consults Expressing Code n (%)		Sample Quotation
	All	Total=49	Patient	n = 245	Patient	Total=40	Non-Patient	n = 32	Non-Patient	Total=9	Non-Patient	Total=9	
Culture-Specific Beliefs^{b,c}	1 (2)		5 (2)		5 (13)		0		5 (13)		0		<ul style="list-style-type: none"> • “The family is familiar with a culture in which bribery is the modus operandi; the father has even offered the attending physician a bribe.”
JUSTICE^a	5 (10)		16 (7)		12 (30)		2 (6)		12 (30)		2 (22)		
Obligation to Treat^{b,c}	3 (6)		7 (3)		7 (18)		1 (3)		7 (18)		1 (11)		<ul style="list-style-type: none"> • “Child comes from a developing country. Concern was expressed that even if the child survived treatment he would not be able to safely return to his rural home. Is it ethically permissible not to offer a bone marrow transplant to this patient?”
Resource Allocation^{b,c}	4 (8)		9 (4)		9 (23)		1 (3)		9 (23)		1 (11)		<ul style="list-style-type: none"> • “A question arises about the validity of using ICU resources for a patient with no apparent chance for recovery.”
PROFESSIONAL RESPONSIBILITY^a	20 (41)		42 (17)		33 (83)		21 (66)		33 (83)		9 (100)		
Fiduciary Responsibility^b (Duty / Obligation to Patient Interests, Issues of Conscience)^c	13 (27)		29 (12)		29 (73)		7 (22)		29 (73)		7 (78)		<ul style="list-style-type: none"> • “The mother’s demands ... triggered a crisis of professional integrity for Dr. J ... who felt duty-bound to do no harm to his patient, who would be burdened by the interventions without opportunity to benefit from them...”
Truth-Telling & Confidentiality^b (Withholding or Disclosing Medical Information, Privacy/Duty to Warn)^c	4 (8)		6 (2)		6 (15)		6 (19)		6 (15)		5 (56)		<ul style="list-style-type: none"> • “What should we do when, in the course of control-subject research participation, medically significant findings are discovered? To whom should such findings be reported and what mechanism should be used?” • “She is unclear about using information she heard in a closed, confidential meeting outside her professional responsibility as a nurse” (about recognizing a blood donor who had disclosed IV drug use at an Alcoholics Anonymous meeting).
Disclosure (Medical Errors, Conflict of Interest)^{b,c}	3 (6)		3 (1)		3 (8)		3 (9)		3 (8)		3 (33)		<ul style="list-style-type: none"> • “Is it ethically acceptable for the physician to perform surgery on this patient, given his supervisory relationship with this patient’s father?”

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Coding Lexicon: (Domain ^a , Subdomain ^b , Code ^c)	Primary Reason(s) for Consult n (%)	Times Code Appeared n (%)	Patient Consults for Whom Code Appeared n (%)	Times Code Appeared n (%)	Patient Consults for Whom Code Appeared n (%)	Non-patient Expressing Code n (%)	Sample Quotation
	All	Patient n = 245	Patient Total=40	Non-Patient n = 32	Non-Patient. Total=9		
Research Conduct / Human Subjects Protection^{b,c}	Total=49 5 (10)	4 (2)	4 (10)	5 (16)	5(56)	<ul style="list-style-type: none"> • "If the child is otherwise eligible, one must then ask if the burdens of the research trial are in the child's best interests when these burdens are compared to other treatment approaches with curative intent." 	

Abbreviation: ALL, Acute Lymphoblastic leukemia; BMT, Bone Marrow Transplant; 6-MP, Mercaptopurine

Table 2

Demographics of Clinical Patient Consultations

Patient Sex (n=43)	n (%)	Patient Location (n=43)	n (%)
Male	23 (53.5)	Outpatient	25 (58)
Female	19 (44.2)	Inpatient	18 (42)
Unknown/Unavailable	1 (2.3)	Pediatric intensive care unit	9 (21)
Patient Age^b (n=43)	n (%)	Patient Age^b (n=43)	n (%)
0 to 7 years	12 (27.9)	18 years	12 (27.9)
8 to 12 years	6 (14)	Unknown/Unavailable	1 (2.3)
13 to 17 years	12 (27.9)		
Primary Hospital Clinic	Patient Diagnosis (n=43)		n (%)
Infectious Disease	HIV		1 (2.3)
Neuro-Oncology	GBM, Medulloblastoma, Spinal Tumor		3 (7.0)
Hematology	Aplastic Anemia, Sickle Cell Disease		4 (9.3)
Leukemia/Lymphoma or Transplant	ALL, AML, Hodgkin Disease, HLH, MDS, Osteopetrosis		17 (39.5)
Solid Tumor	Angiosarcoma, Neuroblastoma, RMS, Rhabdoid Tumor, Soft Tissue Sarcoma, Wilm's Tumor		18 (41.9)
Consult Information (n=44)	n (%)	Requestor of Ethics Consult (n=43)	n (%)
Coded via Directed Content Analysis	40 (90.9)	Physician /Hospital Admin.	36 (83.7)
Consult excluded (data incomplete)	4 (9.1)	Nursing	4 (9.3)
Consult Involved a single patient	43 ^a (97.7)	Anonymous (likely nursing)	1 (2.3)
Consult Involved patient & sibling	3 (6.8)	Donor Advocate / Ombudsperson	1 (2.3)
Consult Involved Hospital Legal Svcs (n=40)	9 (22.5)	Patient or families	0 (0)
Consult Involved Child Protective Svcs (n=40)	6 (67)	Unknown/Unavailable	1 (2.3)
Chaplaincy Involved (n=44)	n (%)	Role of Chaplaincy (n=33)	n (%)
Yes	33 (75.0)	Member of Consult Team	26 (78.8)
No	5 (11.4)	Member of Interdisciplinary Team	4 (12.1)
Unknown/Unavailable	6 (13.6)	Both Roles Present	3 (9.1)

(ALL = Acute Lymphoblastic Leukemia; AML = Acute Myeloid Leukemia; GBM = Glioblastoma Multiforme; HIV = Human Immunodeficiency Virus; HLH = Hemophagocytic Lymphohistiocytosis; MDS = Myelodysplastic Syndrome; RMS = Rhabdomyosarcoma)

^a A single patient had 2 unrelated ethics consultations.

^b Mean patient age at time of consult, 12.4 y; range, 9 mo. – 28 y.

Table 3

Requests for Ethics Committee Consultation about Institutional Policy

Year	Requesting Department	Topic of Consultation Request	Consultation Outcome
2004	Hematology	Recommendations for identifying medical neglect in a high-risk patient population: when is non-compliance with recommended care for children with sickle cell disease medical neglect	Reduction of conflict among members of hematology department, incorporated into internal departmental policies
2007	IRB	Recommendations for managing assent for research trials in children with HIV whose diagnosis has not been fully disclosed to them	Institutional guidelines for assent should not be bypassed. In the event a child > age 7 would otherwise be involved in the assent process, they should not be enrolled on the research study if the family is not willing to disclose diagnosis
2007	Radiologic Sciences	Recommendations for managing incidental findings in control subjects who undergo MR imaging for research purposes	Development of internal departmental policies after input from stakeholders in Radiologic Sciences
2007	IRB	Opinion about when a witness to informed consent is ethically required and what the function of the witness should be in the consent process	Incorporated into internal IRB guidelines; generally the IRB requests advocate be present for therapeutic protocols. The 2013 revision of IRB reviewer forms asks whether or not an advocate is required for consent
2009	Pandemic Task Force Team	Recommendations for resource allocation guidelines for use during a pandemic	Institutional Pandemic Preparedness Plan (PPP) was updated and revision included ethical concerns identified by consultation. Final PPP revision approved by Medical Executive Committee in June 2009
2010	IRB	Recommendations for ethical and practical guidelines for reporting genetic and genomic results to study participants and parents	Used by the IRB as a guideline when reviewing studies involving genomic results. IRB has recently asked HEC for assistance in developing standardized template language for use in research study consent documents that involving genomic research (2013–2014)

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Table 4
 Comparison of This Review with Other Recently Published Studies Quantifying the Nature of Clinical Ethics Consultations

Year Published	Current Study	Moeller	Tappert	Opel	Swetz	Orr	La Puma
	2012	2012	2010	2009	2007	1994	1988
No. of Clinical Consults	40	100	29	71	255	64	51
Pediatrics	Yes	None	No	Yes	No	Yes	No
Patient Age	9 mo – 28 y (Median = 14 y)	26 – 93 y (median 65 y)	1 day – 83 y (median 45 y)	7 days – 21 years	1 day – 94yr (median 68 y)	0 d – 18 yr (47% < 1 y of age)	2 d – 93yr (median 51.7 y)
Inpatient/ICU	42% / 21%	>90% / 64%	100% / 52%	87% / 65% (PICU 35%)	94% / 40%	97% / 94% (PICU 64%)	61% / 33%
Primary Diagnosis	Malignancy (93%)	Respiratory Failure (14%)	Neurologic (24%)	Malignancy (18.3%)	Malignancy (18%) Neurologic (18%)	--	Neurologic (27%)
Multiple Reasons for Consultation	95%	47%	100%	--	--	--	76–90%
Mean # of Issues per Consult	2.5 (primary) 6.1 (total)	2	--	--	--	2.8	2.4 (primary) 3.0 (total)
Most Commonly Identified Issues in clinical ethics Consultations	Fiduciary Responsibility (73%) Best Interests/Proportionality of Risk (73%) Goals of Care (53%)	Family opposed to WD/WH LST (28%) Physician opposed to continuing LST (27%) Capacity or competency concerns (27%)	Initiating hospice care (28%) WH/WD LST (24%) Goals of care (17%) Interfamily conflict (17%)	End-of-life care (62%) Treatment Decisions (31%)	Capacity or competency concerns (82%) Staff or professional conflict (76%) Palliative/end-of-life care (60%)	Decisions to limit treatment (91%) Conflicts about treatment (59%) Quality of Life (27%) Surrogacy questions (27%)	WH/WD LST (49–65%) DNR/POST Issues (37%) Legal issues (30–31%)
Religious¹ / Cultural Issues²	35% ^{1,2}	--	10% ²	15% ^{1,2}	12% ^{1,2}	8% ¹	--

Abbreviations: DNR – do not attempt resuscitation, LST – life sustaining therapy, POST – physician orders for scope of treatment, WD/WH – withdrawing or withholding of therapy
 Pediatric-based studies are highlighted in blue.