

## Why Are There So Few Ethics Consults in Children’s Hospitals?

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**Abstract** In most children’s hospitals, there are very few ethics consultations, even though there are many ethically complex cases. We hypothesize that the reason for this may be that hospitals develop different mechanisms to address ethical issues and that many of these mechanisms are closer in spirit to the goals of the pioneers of clinical ethics than is the mechanism of a formal ethics consultation. To show how this is true, we first review the history of collaboration between philosophers and physicians about clinical dilemmas. Then, as a case-study, we describe the different venues that have developed at one children’s hospital to address ethical issues. At our hospital, there are nine different venues in which ethical issues are regularly and explicitly addressed. They are (1) ethics committee meetings, (2) Nursing Ethics Forum, (3) ethics Brown Bag workshops, (4) PICU ethics rounds, (5) Grand Rounds, (6) NICU Comprehensive Care Rounds, (7) Palliative Care Team (PaCT) case conferences, (8) multidisciplinary consults in Fetal Health Center, and (9) ethics consultations. In our hospital, ethics consults account for only a tiny percentage of ethics discussions. We suspect that most hospitals have multiple and varied venues for ethics discussions. We hope this case study will stimulate research in other hospitals analyzing the various ways in which ethicists and ethics committees can build an ethical environment in hospitals. Such research might suggest that ethicists need to develop a different set of “core competencies” than the ones that are needed to do ethics consultations. Instead, they should focus on their skills in creating multiple “moral spaces” in which regular and ongoing discussion of

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ethical issues would take place. A successful ethicist would empower everyone in the hospital to speak up about the values that they believe are central to respectful, collaborative practice and patient care. Such a role is closer to what the first hospital philosophers set out to do than in the role of the typical hospital ethics consultant today.

**Keywords** Ethics consultation · Children's hospitals · Pediatrics · Ethics committee

## Introduction

In most children's hospitals, there are relatively few ethics consultations (ECs). Kesselheim and colleagues studied 46 freestanding children's hospitals in the United States and found that ECs took place less than once/month (Kesselheim et al. 2010). Thomas and colleagues, in a single-center study, also found a frequency of about one EC per month (Thomas et al. 2015). This relative dearth of ECs is a bit of a mystery because there are many ethically challenging situations in children's hospitals. For example, in fetal medicine, specialists diagnose complex congenital anomalies and discuss choice about termination of pregnancy, innovative fetal interventions, and postnatal palliative care (Antiel et al. 2017; Strong 2003). In the NICU, PICU, oncology, neurology, and many other subspecialty services, doctors, nurses and parents must make decisions about whether to continue life-prolonging treatment or to shift to palliative care (Janvier et al. 2017; Racine and Shevell 2009). Pediatricians deal with adolescents and their emerging autonomy and must decide when or whether to allow them to make health care decisions without their parents' knowledge or input. Small children cannot participate in decisions so it is impossible to rely on patient autonomy. Parents are the default surrogate decision makers but they do not always act in the child's best interest. These are the sorts of dilemmas that, one might imagine, should trigger an ethics consultation. Apparently they don't. The goal of this paper is to speculate about why.

A number of hypotheses have been proposed to explain the relative dearth of ethics consults. Perhaps, as some studies have suggested, clinicians are unaware that such consults are available (Gacki-Smith and Gordon 2005), perceive barriers to requesting a consult (Morrison et al. 2015), or don't believe that ethics consultants are qualified (DuVal et al. 2004). Perhaps clinicians are adequately trained and feel competent to resolve ethical dilemmas on their own (Kesselheim et al. 2008; Cook and Ross 2013). Perhaps ethical dilemmas simply are not being addressed (Pavlish et al. 2015), leading to widespread moral distress (Wocial et al. 2017).

In this paper, we suggest and explore an alternative hypothesis. We believe that, in many children's hospitals, ethical dilemmas are discussed in many different venues and these discussions are of a sort that the creators of ethics committees imagined when such committees were first imagined and created. They are venues that allow and encourage robust ethical discussions of the type that, in the past, might have triggered an EC. Today, those issues are dealt with in other ways.

Ethics consultation, then, is most likely to be called for in the very few cases in which robust discussion among the front-line clinicians and HEC members fails to adequately address the issues or in which, even after discussion, intractable disagreements remain. As a result, in most of the cases that trigger a formal ethics consultation, the issues are ones in which reasonable people disagree and principles conflict. The role of the ethics consultant is not simply to identify or analyze ethical issues. Instead, it is to mediate conflicts and help various parties come to an agreement about a course of action when more than one option is legal and ethically defensible.

In order to illustrate the changing nature of HECs in this context, we will first briefly review the history of HECs. Then we will use a case-study methodology to describe the various ethics activities in children's hospital. These case-studies will be used to suggest directions for further research into the ways that different hospitals parse out the issues of moral distress, medical futility, redirection of care, physician-family disagreements, and the emerging autonomy of older children.

## A Brief History of Ethics Consultation

When ethics committees and the process of ethics consultation were first proposed, in the 1960s and early 1970s, the purpose of such consultation was to bring new voices to conversations about ethically controversial clinical situations. Those new voices were the voices of theologians, philosophers, social scientists, scholars in the humanities, and others. In the early days, there was tension between the traditional physician-dominated model of decision-making and the idea that some decisions could benefit from a multidisciplinary conversation.

Over the years, ethics consultation (by an individual consultant, a team, or a committee) has become widely accepted. Most hospitals in the United States, and many throughout the world, now have ethics committees and a process for ethics consultation. But, in spite of vigorous efforts by various professional societies, the activity remains largely unstandardized. Different ethics consultants have different academic backgrounds (Marshall 1992; Bosk 1999; Thomsma 1991), religious beliefs (Bandini et al. 2017; Brierley et al. 2013), moral commitments (Casarett et al. 1998; Pellegrino 1999), and styles of consultation (Fournier et al. 2015). Professional societies have defined core competencies for ethics consultation (Aulisio et al. 2000; Tarzian and ASBH Core Competencies Update Task Force 2013), and even taken steps to credential ethics consultants (Smith et al. 2010; White et al. 2014). But most consultants remain unlicensed and uncredentialed and, because controversies remain about the proper training, technique, and measures of quality in ethics consultation, it seems likely that the lack of standardization will persist.

Ethics consultation has always been an unstandardized and somewhat controversial activity. In the late 1960s or early 1970s, when philosophers and theologians first ventured into hospitals, they were grappling with the issues raised by relatively new medical technologies such as mechanical ventilation, renal dialysis, and prenatal diagnosis. These innovative technologies generated new and complex

moral dilemmas. Before mechanical ventilation, there could be no such thing as brain death. Before dialysis and transplantation, kidney failure was inevitably fatal. With these new technologies, doctors and patients both had to start making choices about where, when, and how to die.

Many people also realized that traditional medical education was not designed to help physicians think through the ethical issues associated with these new technologies. One solution was to invite in theologians, philosophers, and social scientists to help physicians think about these complicated ethical issues. Early advocates of the collaborative approach included William Ruddick and Benjamin Freedman. In 1981, Ruddick described a project in which philosophers were invited into hospitals to collaborate with doctors and others (Ruddick 1981). The initial job descriptions for the philosophers were vague, but they soon found themselves teaching medical students, serving on hospital committees, and deliberating about “hard cases.” Ruddick characterized “hard cases” as ones that challenged usual professional assumptions. As an example, he described a case in which a 5-year-old child became brain dead after an operation. He wrote,

Some medical staff were inclined to decide the issue of continuing life-support by asking: what would I want for my child in these circumstances? Others rejected that question as tending to suppress any relevant differences between the child’s parents and the doctor - differences, for example, in the value they placed on minimal life without mental capacities, in their belief in miracles, in their emotional reactions and resources. The philosopher posed a different question: what do the pediatric staff owe the parents under the circumstances? (p. 16)

He suggested that the philosopher’s role might be to reframe questions and, in doing so, perhaps generate insights that might not have been generated by the physicians themselves. He recognized that, in doing this activity, philosophers had to carefully balance their roles as both insiders and outsiders, members of the team but also critics of traditional ways of thinking.

Freedman also noted that philosophers who worked in the clinical setting had to be careful about the boundaries of their role. He noted, “The job of the (ethics committee) is to provide a forum in which professionals can discuss their views regarding a particular case. The one overriding theme of our meetings has been: we make no decisions” (Freedman 1981, pp. 20–21). The reason for this was also reticence. The ethics committee, Freedman noted, did not want to become “a roving bank of meddling, ignorant do-gooders” (p. 21).

Physicians warned philosophers to be aware of their limitations. Neonatologist Alan Fleishman wrote, “The philosopher must not be viewed as an expert who has the correct answer, but rather as a clarifier of the process, who can articulate principles of ethics and concern for patients’ rights... The physician must learn that an ‘ethical consultation’ does not result in a directed course of action, but rather provides an understanding of alternatives based on ethical principles” (Fleishman 1981, p. 18). Internist Mark Siegler also offered cautionary advice for humanists on the wards (Siegler 1981). He suggested that they “should be modest in their expectations and should neither exaggerate nor overestimate their importance”

(Siegler 1981). Furthermore, he noted, “The humanist-ethicist lacks technical medical knowledge, has not been prepared in the ethic of human caring, has no responsibility or accountability for decisions made, and is not sanctioned by the patient to be making such decisions” (Siegler 1981, p. 19). He concludes that, because of humanists’ limited knowledge, experience, and accountability, “the presence of humanists on the wards may generate some serious changes in medical care, not all of which will be clearly beneficial” (Siegler 1981, p. 20).

In spite of the wariness of both philosophers and physicians, most hospitals formed HECs and clinical ethicists became an accepted part of the medical care. Today, most hospitals in the US have an ethics committee or ethics consultants, as do many hospitals in Shanghai (Zhou et al. 2009), Brazil (Goldim et al. 2008), Israel (Wenger et al. 2002), the UK, and many other countries. But studies reveal great variation in the composition, the frequency of consultation, the scope of activities, and the mission of HECs.

## Ethics Consultation in Children’s Hospitals Today

Ethics consultation is a mechanism “to help patients, staff, and others to resolve ethical concerns” (Fox et al. 2016, p. 13). The process of discussing and resolving ethical issues begins with consideration of the ethical beliefs of the patients, families, and professionals who are involved in a case. Different people, of course, have different values and priorities, and ethical dilemmas generally arise because these different values conflict or because shared values are prioritized differently.

Institutions also have values. Those values are written into the mission statements of the institutions. Some are devoted to research, others prioritize patient care. Some are private, some are public. Hospitals serve their communities, and different communities may have different values. Streuli and colleagues suggest a harmonizing role for ethics consultation when they note that ethics consultation works only when there is “an underlying institutional clinical ethics framework embodying a comprehensive set of transparently articulated values and opinions” (Streuli et al. 2014, p. 629). But this view underestimates the importance of the day-to-day discussions of ethical issues outside of formal consultations that undergird the successful functioning of an institutional ethics framework. Ethics consultation is as likely to reflect and reify the fundamental values of the institution as it is to create or even articulate those values in a particular context.

All of these factors may lead different hospitals to develop different policies about issues like prenatal counseling, medical futility, or the provision of innovative treatment. For example, in some hospitals, palliative care is offered as an option for babies with hypoplastic left heart syndrome, while in others it is not (Mavroudis et al. 2011). For babies born at 22 weeks of gestation, some hospitals will attempt resuscitation on all babies, some on a subset, and some on none (Rysavy et al. 2015). Societal norms and laws constrain the practices of both hospitals and institutions.

An ethicist in any particular hospital must then create a way to acknowledge, respect, and honor the different values of different individuals who are working or

receiving care within the context of a particular institution and its ethos. There are many mechanisms that can also achieve this goal. A formal ethics consultation is one but we suspect that most hospitals have many others. In fact, other mechanisms may predominate, with ethics consultation used only as a last resort to mediate intractable disagreements (Fiester 2014).

With this complex set of goals and loyalties in mind, we now describe the mechanisms that have been developed in one children's hospital. This "case-study" is not meant to suggest that our hospital is typical or that others should follow our examples. Our hospital's approach may or may not be similar to that in other hospitals. Each hospital probably has its own mechanisms for identifying and addressing ethical issues, creating an understanding of the ethical environment in the children's hospital that can look beyond ethics consultation. Instead, this case study is meant to suggest that, in analyzing how any hospital deals with the ethical dilemmas that inevitably arise, it is worth examining not just the HEC or ethics consultation services but also to seek a thicker description of the various other ways that institutions develop to fulfill the function that was originally imagined for HECs.

### **Case Study of One Hospital's Multi-faceted Approach to Ethical Issues**

Children's Mercy (CM) in Kansas City, MO, is a 301 bed, private, not-for-profit, non-religious children's hospital. CM offers a wide spectrum of tertiary care services, including neonatal and pediatric intensive care, clinical subspecialties, heart, liver, kidney and bone marrow transplantation, as well as emergency care, urgent care, and primary care.

In order to identify the different mechanisms and venues in which ethical issues are routinely discussed, we interviewed the Ethics Committee Chair, five ethics consultants, and staff service area leaders (e.g., ICU directors, specialty Division representatives, and nursing leaders) across the hospital. They identified six venues that were explicitly designed to address ethical issues. These six are (1) the ethics consultation service; (2) the monthly meeting of the hospital ethics committee; (3) the monthly meeting of a nurse ethics forum; (4) monthly ethics workshops open to the entire hospital; (5) semi-annual Grand Rounds lectures; and (6) monthly ethics discussions in the PICU. Three venues have other primary purposes but are places where ethics issues are regularly addressed. These three are (1) weekly meetings of the palliative care team; (2) monthly case conferences in the NICU; and (3) multidisciplinary case conferences in the fetal health center.

In order to characterize these venues and the types of ethical issues that arose in each, we reviewed minutes and other records from each venue for calendar year 2014. We were able to determine who attended these meetings, the topics that were discussed, and, in many cases, the outcomes of these discussions. After discussing each forum, we will describe two examples of complex cases and how the discussion of those cases took place in multiple venues.

The Hospital Ethics Committee (HEC) began in 1978 as a subcommittee of the medical staff. HEC members are now drawn from clinicians in medicine, nursing,

and allied health professions, as well as philosophers, lawyers, chaplains, and administrative staff. The HEC meets monthly. It is responsible for continuing education about ethics throughout the institution. It serves a key role in developing hospital policies. In addition to monthly meetings, the HEC has an annual retreat. At the most recent retreat, HEC members participated in a training workshop on mediation skills and practices.

A self-selected subset of HEC members serve as ethics consultants. Among HEC members who serve as ethics consultants, at least one is always on-call and, when consulted may respond individually or convene an ad hoc meeting of the committee. Consultants meet with patients, family members and health professionals and write a formal consult note in the patient's medical record. In 2014, there were 12 formal consults and another 7 "informal consults," that is, contacts with the ethics committee or its members to discuss issues impacting patient care or communication issues. The most common reason for ethics consultation was disagreement about the appropriateness of continued life-sustaining treatment.

In 1988, the Nursing Ethics Forum (NEF) was created by a group of nurses interested in the impact of ethical issues on nursing practice and patient care. It was created because many nurses felt that there were ethical issues unique to nursing that could best be discussed in a forum for nurses. The NEF meets monthly, and two of its members serve on the HEC. Issues that are brought to or that arise in the NEF meetings may lead to ethics consultations. They also may lead to changes in education or policy. In 2014, the NEF dealt with a wide variety of issues, including moral distress, patients' rights to information about their diagnosis and prognosis, and the allocation of scarce resources. Each month, the NEF meeting includes an "area report" in which a nurse brings issues or concerns from his or her area of clinical focus or unit in the hospital, as well as ethics self-education. Each year, the NEF holds a day-long retreat that provides a more robust forum for ethical discussion and education. In 2014, the topic for the retreat was incivility within nursing and its impact on nursing practice.

A monthly ethics Brown Bag Workshop began in 2006 as a relatively informal, discussion-based forum. Each month, at the workshop, a short presentation by a speaker is followed by interactive discussion. Its intended audience is extremely broad, including members of the HEC, clinicians, and any other hospital employees. Topics and discussions have included the scarcity of life-saving chemotherapeutic agents and possible solutions, ethical issues surrounding the treatment of patients with Ebola, and informed consent for tracheostomy among children with severe neurodevelopmental impairment, among many others.

Each academic year, two of the weekly hospital-wide Grand Rounds presentations are reserved for a presentation about ethics. HEC members are responsible for choosing topics and inviting speakers. Recent topics included ethical issues around death and dying in a children's hospital, controversies in organ procurement and allocation, and the dilemmas of caring for young adults in children's hospitals.

The PICU Ethics Forum began in 2012 as a monthly meeting of interdisciplinary PICU clinicians joined by members of the HEC. It originated as a means to address improved patient care, interdisciplinary team collaboration and communication identified by PICU nurses who were members of the NEF. It serves as a forum for

PICU doctors and nurses to address specific cases, as well as general issues. In 2014, topics included doctor-family communication, organ donation after cardiac death, informed consent for extracorporeal membrane oxygenation, and the allocation of scarce PICU resources.

The Palliative Care Team (PaCT) weekly Case Conference began in 2003 as a meeting of clinicians following an interdisciplinary team model from the hospice and palliative care world. The Medical Director of the PaCT and one of the team nurses are members of the HEC. In 2014, the team provided 238 new patient consultations. Each of these was discussed at least once in the weekly case conferences. Ethical dimensions of patient and family care, as well as team and consultant interactions, are a regular component of these meetings. Members of the referring clinical team are invited to attend.

The NICU Comprehensive Care Rounds (CCR) began in 2011 as a meeting of unit-specific interdisciplinary neonatal clinicians. Its goal is to address optimal communication needs for those caring for complex patients and to encourage all NICU staff to build a culture of safety and quality. Meeting monthly, it often provides recommendations regarding specific ongoing clinical cases brought by clinicians. The CCR meetings often address moral distress, team cohesiveness, and communication among different disciplines. In 2014, the CCR met 11 times and discussed 10 different patients (Boos et al. 2010; Okah et al. 2012).

The Fetal Health Center (FHC) developed at CMH in 2011 deliberately employed a model of interdisciplinary and integrated consultation for women and their families seen in the center. This arose as a means to address the necessarily interdisciplinary management of complicated pregnancies. Its purpose has been realized in holding interdisciplinary consults with the family wherein complex fetal diagnoses are addressed by multiple specialists at a single point in time, parents are informed and contribute to developing a care plan, and a comprehensive letter for referring obstetricians with recommendations is generated. Inherent in the complexity of prenatal diagnosis are ethical and at times palliative care issues that are addressed in the original or subsequent consultation prior to and after birth.

## Synergy Among Different Venues

Most of these venues are not used in isolation. Instead, there is often cross-talk, overlapping membership, collaboration and camaraderie between the various venues within the institution and among the relevant personnel attending them.

For example, an ethics consultation was called regarding a case in which parents insisted on continued treatment when some staff thought that such treatment was not in the child's best interest. This led to a broader discussion of the best interest standard at the following month's HEC meeting. The case was also discussed in the NEF, where conversation focused not just on the specific case but on ways that the institution might better address conflicts between family values and a child's interests.

A second example involved a case from the fetal health center. A 24 week ultrasound revealed that a fetus had multiple congenital anomalies, including a



congenital diaphragmatic hernia, cleft lip and palate, and a critical coarctation of the aorta. The FHC clinical staff invited members of both the HEC and PaCT to help doctors and parents sort through the treatment options. Parents chose to continue the pregnancy with a plan for palliative care in the delivery room. On delivery, the baby was not as sick as had been anticipated. She was stabilized and admitted to the NICU. She remained in the NICU for nearly a year. Her case was discussed in the NICU CCR and a plan was made to not escalate her medical treatment and to facilitate a compassionate life support withdrawal from the ventilator if her condition worsened. A few weeks later, she became more hypoxic and the ventilator was withdrawn. The case was later discussed in the NEF, addressing the effect and impact on nursing care of the family. While no formal ethics consultation had been requested for this child, ethics consultants were present in discussions that took place in the Fetal Health Center, the PaCT weekly case meeting, and the CCR in the NICU.

## The Architecture of Moral Space

Clinical ethical dilemmas arise when professionals and parents disagree about what ought to be done for a particular patient in a given situation. Such disagreements/dilemmas can lead to interpersonal conflict and moral distress (Hellyar et al. 2015). In order for a children's hospital to deal with such conflict and distress, it must foster respectful discussion of disagreements and dilemmas by people who work together but who may passionately disagree about what should be done in specific cases (Hampshire 2001).

Margaret Urban Walker called ethicists the “architects of moral space within the health care setting” (Walker 1993, p. 33). She also notes that the ethicist is only one of many participants in the process and may not be the most important one. Like any architect, the goal of the ethicist is to design and help create a space where others can flourish. The ethical environment of an institution is created and maintained by all the people who work there. The ethicist can and should catalyze discussions but should not necessarily be the primary participant. The goal should be to create a robust ethical climate within an institution so that concerns about ethics infuse every clinical discussion. Formal ethics consultation may sometimes be necessary, but, in an institution with a robust ethical climate, it should not be necessary very often.

While this paper reports results from one institution, we suspect that our hospital is not unique. We believe it to be likely that, in many other hospitals, as in ours, most discussion of ethical issues takes place outside of formal ethics consultation. If so, it suggests that both the training of ethicists and future research on the competency and quality of a hospital-based ethicist should perhaps not focus on their ability to do consultation. Instead, these should focus on their skills in creating multiple “moral spaces” in which regular and ongoing discussion of ethical issues would take place. A successful ethicist would empower everyone in the hospital to speak up about the values that they believe are central to respectful, collaborative practice and patient care. Such a role is closer to what the first hospital philosophers set out to do than the role of the typical hospital ethics consultant today.

We hope that this description of the ethical environment in one hospital will stimulate other researchers to analyze the ways in which hospitals address the everyday ethical issues that arise in complex institutions such as academic medical centers.

**Authors' Contribution** Dr. BC conceptualized and designed the study, co-drafted the initial manuscript with Mr. MB, reviewed and revised the manuscript, and approved the final manuscript. Mr. MB designed the data collection instruments, and coordinated and supervised data collection, co-drafted the initial manuscript with Dr. BC, and approved the final manuscript as submitted. Dr. JG contributed to the design of the study, carried out the initial analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted. Mrs. AK carried out the initial and subsequent analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. JL contributed to the design of the study, carried out the iterative data analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted.

#### Compliance with Ethical Standards

**Conflict of interest** None of the authors have conflicts of interest to report.

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