The ethics consultation and the pediatric surgeon

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ABSTRACT

The cultural, ethnic, religious, socioeconomic, and educational diversity of the patient population and the expanded surgical options provided by innovation and technology can pose significant ethical challenges. The questions confronting pediatric surgeons and their patients’ families have greater complexity, and both the pediatric surgeon and the family perceive increasing vulnerability and uncertainty. The analysis and management of ethical issues in pediatric surgery cannot simply be extrapolated from the approach applied to adult cases. By reviewing the history of the events that contributed to the creation and utilization of hospital ethics committees and examining the role of the ethics consultant in the context of pediatric surgical care, practitioners and trainees will be better able to address these multifaceted situations.

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History of the ethics consultation

David Rothman, in Strangers at the Bedside, delineates several events that served as catalysts to the development of commissions for medical decision making and ethics committees. This included the 1973 Roe V. Wade decision that maximized parental authority with the legalization of abortion, the enactment of the Vocational Rehabilitation Act and its Section 504 that banned discrimination on the basis of handicap as well as the New England Journal of Medicine (NEJM) publication by Duff and Campbell which reported that 43 (17%) of 299 consecutive deaths occurring in a special-care nursery were related to withholding treatment based on poor prognosis and parental rejection of further treatment.

Families had strong but mixed feelings about management decisions. Living with the handicapped is clearly a family affair...In some cases, families considered the death of the child right for both the child and the family...They asked if that choice could be theirs or their doctors...We do not know how often families and their physicians will make just decisions for severely handicapped children...But we also ask, if these parties cannot make such decisions justly, who can? In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed the creation and utilization of hospital ethics committees to ensure good decision-making practices.

Per the conclusions of the Commission’s report, the American Academy of Pediatrics (AAP) in 1984 issued guidelines for infant bioethics committees, stating that such hospital-based committees “consisting of both physicians and non-physicians can provide consultation and review, ensuring sensitive treatment decisions made in a reasoned, informed, and caring manner.” The Joint Commission on Accreditation of Healthcare Organizations mandated that every healthcare organization in the United States have a mechanism in place to address ethical conflicts, and this requirement is met by establishing institutional ethics committees.

The AAP Committee on Bioethics in 2001 issued their recommendations for the role, membership, and structure of an institutional ethics committee (IEC). The IEC is responsible for clinical ethics consultation, review of policies, and education of professional, administrative, and support staff about ethical issues. Hospital-based IECs should ensure an adequate degree of multidisciplinary expertise for addressing ethical issues specific to pediatrics. The IEC may be asked to help when uncertainty or conflict exists, when questions of moral, legal, or economic justification are raised, when problems of communication seem to be impeding patient care, or when it is simply unclear who to
ask for advice. It is noted that the two characteristic features of an ethics consultation that distinguish it from an informal request for advice or a case-based educational session are the involvement of a patient, family, or both and the documentation in the patient’s medical record. This document states that the AAP supports the view that the recommendations from an ethics consultation are advisory only.8

Definition of the ethics consultation

The American Society for Bioethics and Humanities (ASBH) defines healthcare ethics consultation (HCEC) as the set of services provided by an individual or group in response to patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in a healthcare context.9 The general goal of HCEC is to improve the quality of healthcare through the identification, analysis, and resolution of ethical questions or concerns. Additional goals of the HCEC include promoting practices consistent with ethical norms and standards; informing institutional efforts at policy development, quality improvement, and appropriate utilization of resources by identifying the causes of ethical concerns as well as assisting individuals and the institution in handling current and future ethical problems by providing education in healthcare ethics.9

The ASBH, in the 2nd Edition of Core Competencies for Health-care Ethics Consultation, identifies the types of skills, knowledge, attributes, and emerging process standards that are important for conducting HCEC.9 Ethics consultation can be performed by individuals, teams, or committees. The ASBH suggests that ideally a consultation service should make use of all three models determining which is the most suitable in a particular circumstance. The full-committee model may be most appropriate for controversial consultations that may establish precedent or end up in the media or in the court. The strength of ethics committees is that they are typically multidisciplinary and have broad representation from various groups within an institution. It is important for consultants trained in another professional discipline such as law, philosophy, medicine, or nursing not confuse their roles when performing the consultation, e.g., it is not the role of a physician to generate a differential diagnosis and the lawyer should not provide legal counsel.9

The ethics facilitation approach, advocated by the ASBH, involves two core features: identifying and analyzing the nature of the value uncertainty and facilitating the building of an ethically supportable consensus among stakeholders, (i.e., principled ethical resolution), conceptualized by Dubler and Lieblman.10 The ethical principles are beneficence, nonmaleficence, respect for persons, and justice.11 Respect for persons incorporates two ethical convictions: individuals should be treated as autonomous agents and persons with diminished autonomy (e.g., children) are entitled to protection.12 A “principled resolution” is a consensus that identifies a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts that facilitates a clear strategy for future intervention. In the facilitation approach, the ethics consultant must be able to recognize power imbalances so that everyone has a chance to be heard and to “level the playing field” to minimize disparities of power, knowledge, skill, and experience that separate the healthcare professional, patient, and family.9 The principled resolution combines the strengths of a meditative process that levels the playing field with ethical conventions and legal norms and uses both to attain consensus. The “right” substantive decision is ultimately the responsibility of the ethically appropriate decision makers, generally the parents in pediatric cases, the healthcare professional, or occasionally a combination of both. Some cases will have several options that are all ethically justifiable and consistent with prevailing ethical and legal standards.9

Just as pediatric surgery is not operating and caring for little adults, the ethical issues faced by pediatric surgeons are not same as those faced by adult surgeons. The analysis and management of pediatric ethical issues cannot simply be extrapolated from the approach applied to adult cases. In the adult model, decision making involves the dyad of doctor and patient within a social network of other stakeholders. This model recognizes the preeminent importance of autonomy and self-determination and assumes that an informed, competent patient articulates their wishes. When the patient lacks the capacity to participate in this dyad, surrogates articulate the patient’s wishes based on the patient’s history and past decisions.

The structure of decision making in pediatrics includes a triad of stakeholders; doctor, patient, and parents. Unlike the adult, the pediatric patient lacks an established value set.13 The pediatric patient, by law, is not able to independently make healthcare decisions; however, based on their developmental capacity, the pediatric patient is expected to participate in decision making. This developmental capability may be difficult to completely measure or ascertain, yet there is general agreement that the pediatric patient’s assent or dissent has a role in the decision-making process.14 The parent is the default proxy decision maker because they are presumed to have the greatest understanding of the child’s best interest based upon their intimate relationship with and knowledge about the child. There remains the possibility of bias on the part of the proxy decision maker, therefore the pediatric physician must act as an additional safeguard for the child by evaluating if the parental decision is in their patient’s best interest. The degree of advocacy executed by the pediatric physician represents another difference between adult and pediatric decision making. In the context of cultural or religious diversity, children may be multiply vulnerable, as patients, minors, and minorities. It is important for the pediatric surgeon to ascertain that third parties that serve as cultural or religious liaisons have the child and family’s best interest as the priority.15

In what context do ethical conflicts emerge in pediatric surgical care?

In the natural order of life, children are not supposed to die. The acute nature and unpredictability of childhood disease and illness engenders emotional responses from parents and other family and friends which affect decision making in favor of proceeding with aggressive curative therapies.15 Ethical dilemmas may emerge as moral confusion—uncertainty about the right thing to do; moral distress—the right thing to do is known but cannot be done; moral sadness—a morally tragic situation with resultant grief; and frustration that requires debriefing and analysis of where “things broke down.”16

Surgeons are optimistic, action-oriented, and invasive. Operative intervention is viewed as the extreme in the spectrum of care delivered to patients. The surgeon–patient relationship differs from other doctor–patient relationships in that it is more intimate. The patient entrusts their body to their surgeon during an interval of time when they have no communication with their surgeon (i.e., under anesthesia). A parent relinquishes their greatest gift, their child, to a pediatric surgeon. There is a power and authority differential between the surgeon and the patient/family. Due to the pervasive optimism of surgeons, the communication of risk to their patients often reflects a lack of awareness that the patients may have a very different perception of risk.17 The surgeon may be
conflicted by different courses of action, for example, beneficence opposing or in conflict with parental autonomy. When a parent takes a position, we must assume that they want to help their child and help them articulate their values. A patient's family's values and preferences need to put in the context of their culture, religion, and ethnicity. Values may be prioritized differently, and there may be differing and competing concepts of well-being and harm.18 “Beneficence” refers to the physician while “best interest” refers to the patient in terms of the balancing of benefits with harms or burdens. Parents and families may be reluctant to reveal their values and preferences, because they may feel uncertain that they will be well received or respected.19 Surgery may require the family to forego valued healing practices within their culture or those practices that may serve as adjuncts to the surgical procedure.20 It is the physical, psychological, spiritual, and social interests of our patient/families that determine who they are, their outcomes, and the context in which they will flourish. When asked by parents to place a feeding access, a gastrostomy, after years of utilizing nasogastric gavage feeds, the surgeon may feel like a technician; however, the procedure may provide this family with newfound time in their schedule in the care of their special-needs child. One needs to pause and empathize with this family, and realize how difficult it is to make that request, and their fear of possibly being judged as lazy, inept, or selfish for wanting to simplify their lives in this aspect.

Many presumed ethical dilemmas involve neither moral dilemmas nor substantive conflicts about what to do. The major issue is simply failed communication.20 The triggers that prompted interns to obtain ethics consultations were not for the identification and analysis of ethical issues but for conflict resolution, assistance interacting with a difficult family, patient, or surrogate wanting assistance with decision making or planning of care, and emotional triggers such as intimidation, frustration, discomfort, or feeling at a loss about what to do.21

The intrusion of business models on health delivery systems and the emphasis on efficiency can result in undue pressure on providers, with less time being allocated to surgical consultations, and ultimately can impact patient satisfaction. Patient/family dissatisfaction stems from inadequate explanations and feelings of being devalued or rushed. The truncation of time in of itself may not be the key element but rather the behaviors that fill that time. Consultations for inguinal hernias were video recorded in an outpatient pediatric surgery clinic to assess pediatric surgeon behaviors in relation to ethical practice. Physician non-verbal behaviors directed toward the parent and those directed toward the child during the physical exam were observed. The behaviors selected for observation were chosen because they were considered to exemplify good doctor–patient communication, reflecting empathy and listening skills. Behaviors were related to elements of ethical practice, specifically, respect for patient integrity (respectfulness and sensitivity) and autonomy (decision making), and informed consent (provision of information and understanding). There was a strong and consistent association between increasing time duration of the consultation and higher ratings on all components of ethical practice. Gender differences were noted; female pediatric surgeons had higher ratings on informed consent and decision making. In this limited study, evidence is offered providing support for the importance of physician behaviors from an ethical perspective. The authors acknowledge that their aim was not to offer a “recipe” of specific behaviors but to highlight that non-verbal behaviors, including imparting relaxed interest, is important for setting the stage for a respectful encounter and ethical practice.22

Chiu et al.23 were the first to identify and quantify the prevalence of ethical dilemmas encountered by pediatric surgery trainees. Conflict between trainee and staff may result from the trainee’s lack of knowledge, expertise, or experience, and from poor communication between trainee and attending staff pertaining to the rationale for the treatment plan. Trainees expressed concern over the intensity and brevity of their specialty training and their initial lack of knowledge and specific technical skills, especially when associated with the nonexistence of assistance or supervision by attending staff. The most frequent source of moral distress encountered during training pertain to end-of-life care; trainees expressed concern toward the pursuit of surgical treatments in “hopeless” situations, particularly when the treatments resulted in additional complications and suffering for the patient and family. Other examples of moral distress recounted included witnessing unprofessional and unethical conduct in their mentors or other staff.

Treatment conflicts may arise because of clinical uncertainty, (e.g., the team is unsure whether the current or proposed treatment will change the outcome), or from ethical uncertainty (e.g., the team may not have clear understanding of what is legally or professionally permissible). In a retrospective review of pediatric ethics consultations in a pediatric intensive care unit, treatment conflicts were significantly more common for children who previously had been healthy than those who were chronically ill. As frequently experienced by pediatric surgeons caring for children that sustain traumatic injuries, it is more difficult to reach consensus on a decision that may lead to death when a child recently has been healthy: reluctance by the families and physicians “to give up.” Both the family and the treatment team may need more time to process tragic events and choices.24

Adherence to ethical principles is a component of the Accreditation Council for Graduate Medical Education (ACGME) competency of professionalism. Surgical training programs are challenged with regard to teaching ethics due to time constraints including the 80-hour workweek, the focus on the acquisition of technical skills, and lack of faculty support. Faculty may base their own ethical decision making on life experiences, the lessons provided by their mentors, and on their own moral values rather than a fundamental knowledge base of ethical principles. While the teaching philosophy of “see one, do one, teach one” may apply to the technical aspects of surgical training, this model does apply to teaching the management of ethical dilemmas.25

The boundary between medical and non-medical indications or “social” and “medical” benefits may be unclear.26 One illustrative case involves the “Ashley treatment.” Reported in 2006, this refers to Ashley X, a 6-year-old non-ambulatory girl with profound and permanent developmental, cognitive, and neurologic disability secondary to static encephalopathy, with development arrested at the level of an infant, whose parents requested growth attenuation, a hysterectomy, and removal of her breast buds. Since birth, Ashley had been cared for in the home by her parents, both college-educated professionals. Ashley had two siblings and was noted to be an integral and much loved member of her family. Her parents desired to continue to care for her at home, but feared that as Ashley grew larger and heavier, homecare would become more difficult for them and would also decrease the likelihood of participation in family events. Hysterectomy would protect Ashley from pregnancy and the discomfort of menses. In addition, one of the side effects of growth attenuation with high-dose estrogen is uterine bleeding making pretreatment hysterectomy an alternative to hormonal management of the bleeding. The surgical removal of her breast buds would guarantee that large breasts, common in the women in Ashley’s family, would not become a source of discomfort when she was secured with straps in her chair.

This unconventional situation was referred to the institutional ethics committee. The meeting was attended by 11 members of the ethics committee, the parents, the patient, and three of the patient’s physicians. The committee reached consensus that that
all three procedures offered a reasonable prospect of direct benefit to Ashley that justified any of the foreseeable and potential harms. After an uncomplicated hysterectomy, and removal of her breast buds, Ashley underwent high-dose estrogen treatments, attaining a final adult height of 4 ft 6 in. and a weight of 65 lbs. 26–28

This case generated widespread criticism from physicians, ethicists, and disability groups. There was concern that parental convenience rather than “best interests” of the child was the reason the parents requested these procedures. 29 Those against treatment argued that the procedures performed on Ashley involved the elective disruption of a healthy growth process and the surgical removal of healthy tissue and organs from a vulnerable child that would not be subjected to the modifications were she not particularly vulnerable. 30 Those who defended the decision to perform the surgery argued that since resources are not adequately provided to families caring for developmentally compromised children, Ashley’s parents, with the demands of their employment and other family members, were taking the only option open to them. 31 The ethics committee believed that the treatment offered a net benefit to a particular patient based upon that patient’s individual needs. 26 While the committee did not feel this was the situation with Ashley, as pediatric surgeons and patient/family advocates, we must be aware of the possibility of abuse of when parents request medical and surgical interventions for social, cultural, familial, or esthetic reasons. This subordination of a child for parental purposes is different from the parent that elects or refuses treatment for a sick or injured child. 32 Ashley’s case also serves to illustrate that the involvement and decision of an ethics committee may be controversial.

The role of the ethics consultation in pediatric surgery

In requesting an ethics consultation, it is important to ask, “What questions are being asked?” and, perhaps more importantly, “Are they the right questions?” Often the ethics consultant must reframe the case delineating the ethical issues in more specific terms. The primary goals of a clinical ethics consultation are to help patients and providers understand which options are ethically required, which are ethically permissible, and which are ethically unsupported, and assist the shared decision-making process. Surgeons as healthcare providers are in a position of authority and at times may disregard, undervalue, or be unaware of patient/family preferences. Alternatively, the patient/family may be in the dominant position and fail to consider the perspectives of the surgeon. At times the patient/family may view the surgeon simply as a technician and demand interventions that surgeons do not believe will be in the best interests of the patient in terms of benefits vs. harms. 33

As pediatric surgeons our focus and commitment are in the best interests of the child; however, we must acknowledge that other stakeholders, the family, and other members of the care team may view the situation from another perspective. The role of the ethics consultant is to reframe and restructure the patient/family–doctor relationship. The utilization of a third party, the ethics consultant, shifts the locus of power. In the clinical context, decisions need to be made. A patient/family’s values cannot be “mediated” but an ethics consultant can help us acknowledge, work with, and sometimes work around these values. Ultimately the power can be shared, and both patient/families and physicians are given the ability to live with a given decision. The fact that parents and a physician agree on a procedure or course of action does not ensure that the course is ethically advisable or even permissible. If the committee concludes that the parents and doctor(s) have together reached an inappropriate decision, then that conclusion needs to be shared and explained. In general, the values of the patient/family guide the decision making. The parental decision is supported whenever feasible. 33 Another goal of ethics consultation should be to address palliative care. Focusing on limiting inappropriate use of medical technology emphasizes what physicians will not do for the patient rather than what they can do to palliate physical, psychosocial, and spiritual distress. 34

Ethics consultation in an educational capacity can guide both trainees and faculty in the integration of skills such as clarifying clinical issues, analyzing bioethical issues, and communicating effectively. 34 An important consideration regarding the educational aspect of ethics consultation is the enhanced opportunities for ethical reflection, learning, and insight. This may reduce moral distress and burnout and ultimately have beneficial effects on clinical outcomes. 35

Pitfalls in ethics consultations

Studies evaluating the effectiveness of ethics consultations initially focused on the views of physicians regarding the utility of ethics consultants and committees. Subsequent studies have explored ethics consultations from the perspective of patients and families. A prospective, multicenter randomized controlled trial in the adult intensive care setting evaluated the effect of ethics consultations on life-sustaining treatments in response to value-laden conflicts. Ethics consultations were useful in resolving conflicts that may have inappropriately prolonged nonbeneficial or unwanted treatments in the intensive care unit. 35

A retrospective study at a pediatric teaching hospital compared the opinions of physicians and families to determine whether ethics consultations were helpful; specifically whether they found the ethics consultant helpful in identifying, analyzing, and resolving ethical conflicts and whether they were ultimately satisfied with the medical decisions that were made. The majority of physicians and social workers found the ethics consultation helpful; however, the family satisfaction was mixed. From the caregiver’s perspective, positive comments expressed gratitude for the “hand-holding” provided to the physicians making difficult decisions and noted that the consultation allowed different staff members to voice their ideas on the situation and on their personal conflicts. One social worker commented that the process of the consultation was the first time the family was offered choices that they wanted but did not know how to articulate. Negative comments by physicians expressed that ethics consultants can disrupt teamwork and cause stress among the caregivers. Parental anger can be transferred to the ethics consultant. One mother in this study recounts that the role of the ethics consultant was not well communicated to her. In this situation, the failure to explain the role of a third party such as the ethics consultant only increased the gap in communication. Additionally, the ethics consultant may be the first to deliver “bad news” or introduce the full range of treatment options including alternative therapies that may be distressing for the family to contemplate, especially when presented by a stranger. 36

Every consultation aims for the good of the patient. The ethics consultation may be the only time that all decision makers and stakeholders—patient/family, surgeons, nurses, social workers, and religious leaders—are assembled. It provides the rare opportunity for a true interdisciplinary dialog of the patient/family, problems, concerns, and needs. The primary goal of an ethics consultation is a better decision or action for the patient. As highlighted by the Ashley case, there may be a difference of opinion among ethicists where some feel the best interest standard requires weighing the benefits and burdens to the patient only, while others may believe that the interests of others affected by the decision (e.g., the family as an entity) should also be taken into account. 37 The ethical analysis may be viewed as too abstract, out of context, or divisive. There is the risk that the ethics consultants may reach consensus
and feel “comfortable” in the process of resolving conflict, yet not act in the patient’s interests.36 Per Pellegrino,38 “Keeping the patient’s good in the forefront helps to prevent ‘consensus’ from becoming the major and self-justifying purpose of the consultation.” Ethics consultation often involves an integration of ethical, moral, and legal issues. What is legal may not be moral, and what is moral may not be legal. The purpose of an ethics consultation is a morally good decision for a patient, not the well-being of the health professional or the institution.38

The ASBH acknowledges the necessity of evaluating HCEC services by systematically assessing how the service performs relative to a set of standards pertaining to quality of service, access to the service, and the efficiency of the service. The components of quality of HCEC services include structure, process, and outcomes. The outcomes component refers to the result of the service provided both the positive and negative effects on patients and the benefits and burdens on staff and the institution. Outcomes such as mortality and cost are easily measurable, however, their relevance to HCEC is unclear. Other outcomes such as adherence to ethical principles, patient satisfaction, and employee moral are more difficult to measure but may have greater relevance to the evaluation of HCEC.39 Priorities for future research include determining the most-valued outcomes of successful HCEC, the best type of consultation model (i.e., individual vs. team vs. full committee), the requisite competencies that an individual must have to perform HCEC successfully, and the role boundaries for HCEC services relative to related services such as chaplaincy, palliative care, legal services, and social work.9

Conclusion

Conflict is unavoidable in the context of complexity, uncertainty, ambiguity, stress, and change. Innovation and technological advancement have expanded surgical options creating ethical questions and challenges, while disparities in healthcare access and delivery in the United States have ethical implications for care. The cultural, ethnic, religious, socioeconomic, and educational diversity of the patient population can also pose ethical challenges. As pediatric surgery advances the ethical questions confronting surgeons and families have greater complexity, thereby increasing the uncertainty felt by both families and their healthcare providers. Ethics consultants can help address these contentious issues and should be considered a valued resource as well as an effective conduit for communication. The goal is to attain a “principled resolution” through an amalgam of accepted ethical principles, legal norms, and moral rules. The healthcare ethics consultation should not be considered a measure of last resort when the healthcare team “fails” to resolve the conflict.9 The conclusion made by Duff and Campbell2 in 1972 still holds, “Perhaps more than anything else, the public and professional silence on a major social taboo and some common practices has been broken further. That seems appropriate, for out of the ensuing dialog perhaps better choices for patients and families can be made.”

References