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11.1 Introduction

Pediatric surgeons are often confronted with clinical situations that involve decisions about the continuation of life-sustaining treatments for infants and children with critical illness. These difficult issues fall within the basic social commitment that defines the professional obligation of physicians to sustain life and relieve suffering. Ethics is the philosophic discipline concerned with questions of right and wrong. Medical ethics, also known as bioethics, outlines the standards, principles, and rules of conduct that govern physician behavior and the practice of medicine. It also seeks to inform and guide the resolution of moral dilemmas as they arise in patient care and within the broad context of societal healthcare.

Four major principles have been elucidated in medical ethics: *beneficence*, which exhorts physicians “to do or promote good;” *nonmaleficence*, which cautions physicians “to do no harm;” *autonomy*, which respects the right of competent persons to give informed consent for medical treatment and have control over their bodies; and *justice*, which involves the fair and equitable distribution of medical care to all persons. These principles focus on the action or actions that give rise to dilemmas, such as withdrawing life-sustaining treatment from a terminally ill patient. In contrast, virtue ethics emphasizes the agents (physicians) and the recipients (patients) of principle-based actions and decisions. It espouses several virtues that are necessary for the delivery of “good medical care,” and is particularly relevant to the practice of pediatric surgery. These virtues include fidelity to trust, compassion, phronesis or common sense, fortitude, integrity, honesty, and self-effacement.

11.1.1 What Is a Moral Problem?

A moral dilemma is a type of moral problem that arises when two or more conflicting ethical principles support mutually inconsistent actions. An example of a moral dilemma in pediatric surgery is the conflict between the principles of autonomy and beneficence, when parents decide on a course of treatment for their child that does not align with the recommendations of the pediatric surgeon. Moral uncertainty and moral distress are additional types of dilemmas that may occur in pediatric surgery, especially when the prognosis is unclear for a given condition, when two or more equally valid treatment options are available, or when parents are in disagreement with each other and/or their physicians about the best medical decisions.

11.1.2 Resolution of Ethical Problems

When a moral problem arises in the context of decision making for a given pediatric surgical patient, the members of the healthcare team should work toward a resolution that promotes respect for all parties and all views. As we and others have noted, successful outcomes require that the team: (1) develop common moral language for the discussion of moral issues; (2) have training in how to articulate their views about issues; (3) have common experiences on which to base recommendations; and (4) agree on a moral decision making method for all to use in the course of their deliberations.

The following guidelines provide a framework for the effective resolution of difficult moral problems:

1. Identify the decision makers. For most cases in pediatric surgery, the decision makers will be the parents, unless the patient is a mature minor.
2. Ascertain “value data” from the parents and other relevant family members. These may include their views on the sanctity of life, spirituality and religious beliefs, cultural norms, and community values.
3. Collect all relevant medical information, including the prognosis. Clarify the areas of uncertainty and identify whether additional diagnostic testing would be of value in the decision making process.
4. Define all treatment options, including their benefits, risks, and chances of achieving the desired outcomes.

5. Provide the parents with a professional recommendation for the best treatment option.
6. Seek a consensus resolution that can be accepted by all participants.

In order for the above paradigm to be successful, the healthcare team must accept that rational people of goodwill may hold divergent views that are irreconcilable, even after extended discussions. The goal of reaching a consensus decision should be viewed as a successful outcome for all participants.

11.2 Informed Consent

The doctrine of informed consent is firmly embedded in contemporary medical practice and is based on the bioethical principles of respect for individual autonomy, nonmaleficence, beneficence, and justice as discussed previously.

Respect for patient’s *autonomy* is the guiding principle for informed consent. Autonomy is paramount in mentally competent patients who can exercise the freedom to choose among alternative interventions based on full disclosure of the risks and benefits of these alternatives, and consistent with their beliefs, values, and goals. In children, autonomy is limited when the decision is made by proxies, including parents who are well meaning. Therefore, depending on the circumstances, the *assent* of the pediatric patient should be sought as appropriate to their development, age, and understanding. In addition, most legal jurisdictions have enacted minor consent statutes that seek to determine instances where children can give their informed consent. Apart from the ethical and legal obligation, it is clear that increasing patient autonomy and participation in care is also associated with better outcomes in some situations.

Because the exercise of autonomy is limited, beneficence and nonmaleficence assume greater relevance during the informed consent process in pediatric patients. Thus, pediatric surgeons assume significant responsibility for providing active guidance to parents in protecting the best interests of the child. Unfortunately, during this process conflict may arise between parents and caregivers. Justice is achieved when the tension between parental exercise of autonomy and the imperatives of beneficence is resolved in the best interest of the child.

11.2.1 Elements of Informed Consent

Four critical elements must be included in the informed consent process: (1) The physician provides adequate information with which to make a decision to (2) a competent patient or legal proxy who (3) indicates full understanding of the intervention, including the indications, risks, and possible alternatives and (4) voluntarily consents to the proposed intervention.

11.2.2 Exceptions to Informed Consent

There are several legitimate exceptions to the right of informed consent, including exceptions for medical emergency, public health emergency, the incompetent patient, and patient waiver of consent. The exceptions for emergencies and for patients unable to give consent are particularly relevant to situations requiring emergency surgery. In the case of children, any delay may also have significant negative long-term consequences for growth and development.

Although significant emphasis on the informed consent process has been made in the context of medical research and non-acute medical and surgical treatment, several professional societies have established guidelines for dealing with patients in emergency settings. When immediate action must be taken to prevent death or other serious harm to the patient, the emergency exception mandates that appropriate care not be delayed. Despite the urgency involved, quite often there is ample time for preoperative education of the family, which is essential for a truly informed consent.

11.3 Withholding and Withdrawal of Life-Sustaining Treatment

Life-sustaining treatments include all interventions that prolong a patient's life. These include "high tech" measures such as renal dialysis, ventilators, and organ transplantation, as well as less technically advanced modalities such as antibiotics, fluids and nutrition delivered through enteral tubes or intravenous means, and chemotherapy. Decisions to withhold life-sustaining treatment are generally made in advance and agreed

upon by the parents and physicians. For example, a child with recurrent metastatic neuroblastoma who has already received maximal adjuvant treatment may be offered no additional chemotherapy and referred to hospice care. While many individuals believe it is "worse" to discontinue life-sustaining treatment than to never institute such treatment, ethicists, moral philosophers, and legal scholars find no ethical or legal distinction between not starting treatment and stopping treatment. There is also the very real concern that fear and reluctance about discontinuing life-sustaining treatment could keep some physicians from initiating therapy that may be beneficial for some patients with critical illness. In pediatric surgery, it is generally believed that life-sustaining treatment for an infant or child should be instituted, and it should be stopped if it proves to be of no benefit later.

11.3.1 The Surgical Neonate

"A 3 week old baby boy, born at 25 weeks gestation, develops perforated necrotizing enterocolitis. He has chronic lung disease and a grade 4 intraventricular hemorrhage. At laparotomy he has necrosis of all but 20 cm of jejunum and half of the colon. The bowel is resected and stomas are created. Postoperatively, he develops worsening lung disease and renal failure. The physicians discuss his poor prognosis with the parents and request withdrawal of life-sustaining treatment."

This case typifies an all too frequent ethical dilemma faced by pediatric surgeons when extremely premature infants with multiple medical problems develop necrotizing enterocolitis complicated by short bowel syndrome. When making decisions to prolong life or to discontinue life-sustaining treatment for an infant with critical illness, the *best interests standard* is generally used to focus on issues that are patient-centered and to assess the benefits and burdens of continued treatment for a *particular infant*. In this case the infant's best interests standard would include consideration of:

1. Severity of the medical condition
2. Availability of curative or corrective treatment
3. Achievability of medical goals
4. Presence of serious neurological impairments
5. All associated medical conditions
6. Life expectancy
7. Extent of suffering

8. Proportionality of treatment benefits to burdens in both the short and long terms

Parents of imperiled surgical neonates seek the counsel and advice of their infant's pediatric surgeon, who should make a recommendation based on the medical facts, the parents' values, and the infant's physiological condition. When, as in the present case, continued life-sustaining treatment is judged to prolong the dying process rather than to extend life, the pediatric surgeon should present her/his assessment with candor and compassion. It should be kept in mind that many neonates with extensive bowel loss will be candidates for prolonged total parenteral nutrition in the hope of eventual bowel adaptation and/or intestinal transplantation. Decisions to continue life-sustaining treatment for them should be based upon the pediatric surgeon's assessment of the benefits of such treatment, its likelihood of success, and the anticipated burdens of therapy. In cases where prognostic uncertainty about outcome is high, the parents should be accorded latitude in decision making, whether they choose to continue treatment or to stop life-sustaining measures.

11.3.2 Older Children and Adolescents

Life-threatening illnesses, such as terminal cancer, may impact the developmental understanding of pediatric patients by accelerating their grasp of serious illness and their own mortality and by promoting their wishes to control decisions about their healthcare. The stresses of their illness may "make them grow up faster" and make them wiser than their same-age peer group. For example, a 12-year-old child with terminal cancer may ask to discontinue chemotherapy or other unpleasant treatments and request to have "one final special vacation."

Because children cannot give morally or legally valid consent to or refusal of treatment, practice among physicians in the past was to shelter dying children from the truth of their dire circumstances. Current practice, favored by The American Academy of Pediatrics, acknowledges that these patients usually have a much more mature understanding of their situation than previously realized by their physicians and parents and that they should be told the truth about their prognosis and included in discussions about their care. These discussions should include the extent of

desired life-sustaining treatments, whether a do-not-resuscitate (DNR) status is to be invoked, the role of palliative procedures in granting a better quality of life, and their desire for hospice services.

11.4 Multiculturalism

Cultural practices that are different from the norms of the majority can pose frustrating problems for pediatric surgeons, particularly when they affect parental acceptance of and compliance with recommended treatments. "Culture" is defined as the common and accepted way of thinking, feeling, and acting for a group of people. This includes the full range of accepted beliefs, values, attitudes, patterns of meanings, and behaviors that are held in common by a group of people. Culture is the mechanism by which people navigate and make sense of their world through their shared meanings and patterns of behavior. Because culture is so broad in scope, it cannot be defined solely by political borders, religious practices, or physical characteristics. It is important for pediatric surgeons to understand the importance that culture plays in healthcare because it may elucidate both *how* and *why* parents of a particular culture tend to behave as they do.

It should be emphasized that physicians are socialized by traditional values inherent in Western medical training, which are based on a set of assumptions and values about disease and well-being. For example, the traditional medical paradigm focuses on disease as a malfunction of a biologic process in the patient. In contrast, patients experience illness (including children and their parents) as represented by their personal, interpersonal, and cultural reactions to the disease. Therefore, it is important for the pediatric surgeon to be mindful of her/his own individual cultural beliefs as well as the unique culture within pediatric surgery. In meeting parents and children whose culture is different, the pediatric surgeon should inquire about their beliefs, goals of treatment, and their concerns. The pediatric surgeon should not automatically assume that an individual set of parents from a certain culture will hold all of their beliefs in common with their cultural group. For example, not all Chinese parents believe in or use traditional Chinese medicines or complementary practices.

Language barriers may pose additional difficulties in the multicultural medical setting, particularly when parents want to rely on a family member or older sibling of the patient for translation. The pediatric surgeon should utilize experienced medical translators to ensure accuracy of transmitted information both to and from the parents and child patient, to avoid translation bias, and to help in reading nonverbal and verbal cues about underlying concerns.

When different cultures meet in the pediatric surgical healthcare setting, some aspects of the encounter will include similar values (for example, the parents want good health for their child). However, it is also possible that some important values may be in conflict and have a different set of priorities (such as how the child will recover). The following strategies are useful in lessening cross-cultural conflicts: (1) asking questions about the parents' values and listening to their responses; (2) indicating to the parents that their views are important; (3) allowing enough time to deal with the parents whose culture is different; and (4) seeking assistance from "experts" who understand the parents' cultural beliefs when significant differences arise in the course of treatment.

11.5 Surgical Error

In recent times, the high incidence of medical errors and the significant impact they have on patient outcomes has been in the spotlight. Examples of errors encountered during surgical treatment include wrong diagnosis, wrong patient (or site) procedures, and retained foreign bodies. Pediatric surgeons have an ethical responsibility to inform parents of changes in diagnoses resulting from retrospective review of test results or any other information, even when surgical treatment or therapeutic options may not be altered by the new information. Full disclosure is imperative for errors that are harmful to patients. Nondisclosure has been described as "one of the deadly sins of medical ethics." Disclosure of errors is endorsed by most professional organizations and increasingly required by regulatory and governmental agencies.

Studies have revealed the difficulty that surgeons face in deciding whether and how to disclose harmful errors. Most parents desire an explicit acknowledgment that an error had occurred, what the error was,

how the error occurred, how the error will affect their child, and what efforts are being made to prevent occurrence of similar errors in the future. In addition, most parents desire an explicit admission of responsibility and an apology. Some physicians may feel reluctant to admit error, partly because risk managers routinely advise that error disclosure not include any statement that could constitute an admission of liability. Clearly, considerable skill and tact is often required in the disclosure of errors. However, concern regarding legal liability should not affect the pediatric surgeon's honesty with parents. To the contrary, failure or inadequate disclosure of errors might feed into parents' anger and mistrust, thereby increasing the likelihood of lawsuits.

11.6 Research and Innovation in Pediatric Surgery

Advancements in pediatric surgery have been brought about by research and development of innovative surgical techniques. While it is vital that research endeavors be encouraged, protection of research subjects is paramount. Current ethical standards for the conduct of clinical research in the United States are derived from several sources including the Nuremberg Code and the Belmont Report. Similar standards are in place in most progressive societies. Several of the bioethical principles previously discussed in the context of clinical practice were originally developed to protect subjects in research studies. These principles are applied using informed consent, risk/benefit assessment, the impartial selection of study subjects, and the protection of vulnerable subjects, especially children. Recent implementation of the Privacy Rule now requires the investigator to protect not only the safety but also the privacy of the research subject. In most institutions, compliance with these requirements is promoted by the Institutional Review Board (IRB). In addition, editors of most pediatric surgery journals have joined a growing coalition of medical journals requiring IRB approval prior to publication of results of research studies.

In contrast to clinical research where different approaches to treatment are being tested, surgical innovation entails application of new techniques or therapies, or modification of existing procedures, when deemed to be in the best interest of the patient. In most

countries, drugs and medical devices are strictly regulated, but currently there are no clear regulations pertaining to innovative surgical procedures. Pediatric surgeons have been among the most notable surgical innovators, and many of the procedures beneficial to children today may never have passed the rigor of randomized clinical trials. Yet, too little regulation creates the potential for abuse and can be harmful and dangerous. For example, some operations that have now been abandoned, such as sympathetomy for Hirschsprung's disease and jejunoileal bypass for morbid obesity, may never have been widely used under a stricter regulatory environment.

Parents and society expect pediatric surgeons to be conservative guardians in surgical innovation. A useful approach is to regard any new procedure as *non-validated*, a term that recognizes the ethical and medical hazard of novel operations, which may be obscured by the terminology of innovation. The concept of a non-validated operation is more transparent and honest because it embodies the fact that the proposed operation has not been subjected to rigorous investigation.

Ultimately, this awareness may nudge both parents and pediatric surgeons toward the ideal of multi-institutional clinical trials that seek to establish the best operations or treatment for children.

Further Reading

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