

CHAPTER 1

Ethics and Professionalism in Pediatric Anesthesia

David B. Waisel

Harvard Medical School and Boston Children's Hospital, Boston, MA, USA

Introduction, 1	Forgoing potentially life-sustaining treatment, 7	The pregnant adolescent, 11
The informed consent process for children, 2	Perioperative limitations on potentially life-sustaining treatment, 7	LGBTQI+ patients, 12
The best interest standard and informed permission, 3	Physician orders for life-sustaining treatment, 8	Professionalism in pediatric anesthesia, 12
Informed assent: the role of the child, 3	Barriers to honoring perioperative limitations on life-sustaining treatment, 8	Advocacy and good citizenship, 12
Emancipated minors and the mature minor doctrine, 4	Potentially inappropriate interventions, 9	Safety and quality care initiatives, 12
Disclosure, 4	What would you do in my situation?, 9	Disclosure and apology, 13
Informed refusal, 4	Organ procurement after cardiac death, 9	Production pressure, 14
Children of Jehovah's Witnesses, 5	Special circumstances in pediatric anesthesia, 10	Suspicion of child maltreatment, 14
Emergency care, 6	Research in pediatric patients, 10	Case study, 14
The temporarily impaired parent, 6	Confidentiality for adolescents, 11	Annotated references, 16
Consent for pediatric procedures without direct benefits, 6		
Genetic testing and biobanking, 6		

Introduction

The key to the ethical practice of pediatric anesthesia is: *Treat every child and family with the grace and consideration with which you would want your child and family treated.* Here are seven maxims:

1. *Remember that surgery is a big deal.* Reminding yourself that this banal case is a lifetime event for the child and family helps you be kind and respectful to the child and family. It boosts your ability to mitigate the production pressure that hurries you to induce anesthesia before the premedication has taken effect, inadequately prepare a nervous adolescent for insertion of an intravenous catheter, or skirt safety guidelines.
2. *Meet the needs of the child and family.* Focus on process by being patient, calm, flexible, and nonjudgmental. Anxious, sleep-deprived parents receiving complicated information may need to hear it several times to understand it or may react strongly to the seemingly unremarkable. Interact with the intent of determining their needs, whether it be the extent of information, the preferences for decision making, or the need for reassurance. Respond directly to questions.
3. *Be humble.* As a professional, it is tempting to believe you know what is best. But many of the choices families make reflect values, anxieties, and personal, family, and community experiences that are difficult for you to know, much less appreciate. Denigrating families for choosing what you believe to be a less optimal albeit acceptable choice

ravages professionalism and mars interactions with all patients. If you think a decision is unacceptable, consult with respected colleagues before pursuing administrative or legal interventions.

4. *Assume responsibility for the children and their families.* "Own" care for the child and family to ensure that every little thing goes as well as possible. This includes: bringing a chair for the third adult; finding someone to answer questions unrelated to perioperative clinical care; doing a thorough preoperative evaluation; making the extra effort to insert the IV in a way that does not impede the dominant hand; always using the optimal anesthetic technique; being alert for errors in the operating room unrelated to you; and ensuring children and families are physically and emotionally well postoperatively. If you would do it for your child, you should do it for every child.
5. *Serve patients.* Medicine is a noble service profession. For the most part, patients' preferences, values, and needs supersede ours. Our values become relevant only after thorough, thoughtful, and careful consideration and consultation.
6. *Hone your mastery.* Strive to provide first-rate care, critically consider what you know and how you know it, and seek help freely [1].
7. *Use empathic behavior.* Clinicians need to overtly communicate that they understand and appreciate the perspective and experience of the child and family [2]. An effective way to communicate empathy is a heartfelt "I wish things were different" [3].

Although clinicians may think of medical ethics in dramatic terms – withdrawing life-sustaining therapy, allocating organs for transplant – medical ethics floods our daily practice. Consider the clinician who recommends postponing surgery in an infant because of a borderline upper respiratory infection. Should they be flexible if the infant has missed three surgical dates for non-medical reasons? How should they respond to a parental request to proceed? Within these seemingly medical decisions lie the ethical components of informed consent and obligations to the child and family. How do we decide how much weight to give the parents' strong desire to proceed? Does it matter why they want to proceed (guilt over missing the previous appointments? Concern about their child's health? Convenience because grandma is in town to care for siblings? Concern about being able to get time off from work again? Scheduling because the child will spend the summer with an out-of-town parent, effectively delaying the operation until fall? etc.). Should we even consider the effects on the family? What if there is concern that the parents will not reschedule surgery?

Ethical dilemmas occur when clinicians are faced with "oughts" – that which a physician is bound by duty to do – that conflict. In the above example, clinicians ought to base proceeding with surgery solely on the child's best interest, which may include the effects of the upper respiratory infection and the likelihood that the child will get a timely operation. Medical ethics provides the process by which to resolve these apparently conflicting "oughts."

Resolving ethical dilemmas is not a matter of being a moral person. Identifying, diagnosing and managing ethical conflicts requires the same extent of expertise that is required to identify, diagnose, and manage myocardial ischemia. Training and experience in resolving ethical dilemmas enables ethics consultants to identify the dilemma and critical facts, apply ethical principles and case-based analysis, articulate precise questions, and have the moral imagination to create more palatable solutions.

Despite erstwhile efforts, fewer than 51% of pediatric residents correctly answered questions about some aspects of patient confidentiality, genetic testing, pediatric assent and the ethical similarity of withholding and withdrawing potentially life-sustaining medical treatments (LSMT) [4].

Deficits like these highlight the importance of ethics committees and their consultation services. Clinicians may find consultation services particularly helpful with concerns about disagreements among families and clinicians, appropriate decision-making roles for adolescents, decisions about end-of-life care, and professional obligations [5,6].

Members of ethics committees include representatives from throughout the hospital such as chaplains, administrators, social workers, nurses, and physicians. Many committees also include local community representatives. Depending on local practice, consultations may be performed by an individual, a small group, or the entire ethics committee. Most ethics consultation services permit anyone with standing to request a consultation, which fundamentally includes all clinicians who participate in the care of the patient [5]. Most services enter a written report into the clinical record. The standard of care is that ethics consultation services advise only and have no formal authority. A committee with a strong record, however, has substantial informal authority. The case study provides an example of an ethics consultation.

The law is not a desirable substitute for resolving ethical dilemmas. The law represents a lower bound for acceptable behavior; whereas ethics articulates a standard to which we should aspire. Pragmatically, the law does not provide clear guidance because most law surrounding ethical dilemmas is case law. In addition, the frequently adversarial legal process may pollute future family–clinician–hospital relations. Crude statutes and regulations are unable to govern complex medical care.

KEY POINTS: THE ETHICAL PRACTICE OF PEDIATRIC ANESTHESIA

- Pediatric medical ethics is a broad and changing field
- Identification, diagnosis, and management of ethical issues requires expert knowledge, experience, and skill
- Anyone involved in a patient's care can request an ethics consultation

The informed consent process for children

The doctrine of informed consent centers on the belief that patients have a right to self-determination. The right to self-determination is actualized through the legal concept of competency. Except in specific situations, minors are not legally competent to consent for healthcare. But minors do have varying degrees of decision-making capacity, and minors should be included in medical decision making to the extent permitted by the child and situation (Box 1.1) [7].

The process of pediatric informed consent depends on the age and development of the child (Table 1.1). The concepts

Box 1.1: Elements of consent and assent as defined by the American Academy of Pediatrics [7]

Elements of informed consent for medical decision making

- Provision of information about the following:
 - Nature of the illness or condition
 - Proposed diagnostic steps and/or treatments and the probability of their success
 - The potential risks, benefits, and uncertainties of the proposed treatment and alternative
 - Treatments, including the option of no treatment other than comfort measures
- Assessment of patient and surrogate understanding and medical decision-making capacity, including assurance of time for questions by patient and surrogate
- Ensure that there is voluntary agreement with the plan

Practical aspects of assent by pediatric patients for medical decision making

- Help the patient achieve a developmentally appropriate awareness of the nature of the condition
- Tell the patient what to expect with tests and treatments
- Make a clinical assessment of the patient's understanding of the situation and the factors influencing how they respond (including whether there is inappropriate pressure to accept testing or therapy)
- Solicit an expression of the patient's willingness to accept the proposed care

Table 1.1 Graduated involvement of minors in medical decision making

Age	Decision-making capacity	Techniques
Under 6 years	None	Best interest standard Harm threshold standard
Ages 7–11 years	Developing	Informed permission Informed assent
Ages 12–18 years	Cognitive skills developed Maturity developing	Informed assent (approaching informed consent as developmentally appropriate) Informed permission
Mature minor	Developed, as legally determined by a judge, for a specific decision	Informed consent
Emancipated minor	Developed, as determined by a situation (e.g. being married, in the military, economically independent)	Informed consent

This broad outline should be viewed as a guide. Specific circumstances always must be taken into consideration. When children are in the upper range of an age bracket, limited or full inclusion of a more developmentally advanced technique, such as the use of assent for a 6-year-old, may be appropriate.

of best interest, informed permission, and assent are used when considering pediatric informed consent. For convenience, the term “parent” will be used to describe the child’s surrogate decision maker. Parents are not always the legal surrogate decision maker and parental authority may be limited in adolescents. The term “decision makers” will refer to those involved in the specific decision and may include parents, children, and their advisors.

The primary lesson of this chapter should be to respect the experiences and opinions of children. The American Academy of Pediatrics emphasizes that “no one should solicit a patient’s views without intending to weigh them seriously. In situations in which patients will have to receive medical care despite their objections, the patient should be told that fact and should not be deceived.” [8].

The best interest standard and informed permission

Informed consent can be given only by the patient. Some advocate for the term “informed permission” for when the parent provides legal consent and ethical decision making for the child, to emphasize that the consent is not by the patient [8]. This conceptual framework highlights the ethical limits of parental decision making. It does not affect the legal obligation to obtain informed consent from the parents as defined by local statutes.

Children younger than the age of 7 typically have insufficient decision-making capacities to participate effectively in the informed consent process. When children cannot effectively participate, or when parents are unable to base a decision on previous interactions with the child, the best interest standard traditionally guides decision making. This standard requires determining who will make the decision and what is in the child’s best interest. Best interest does not mean the best care as defined by the clinicians. There are often several acceptable options, and clinicians rely on parents to determine which one is in the child’s best interest. Parents are given considerable latitude in decision making because society values the role of family, parents want the best for their children, and families often have to live with the result of the choices. Although parents may be wrong in determining the preferences of their child’s future self, many accept that parental values serve as a reasonable approximation of those future values [9].

Parental decisions should be scrutinized if they appear to fall outside of the boundaries of acceptable care. Boundaries are determined by the extent and likelihood of potential harms by the intervention or its absence, the likelihood of success, and the overall risk-to-benefit ratio.

The harm threshold standard may be more accurately named and conceptually useful than the best interest standard for determining whether to limit parental decision making. The harm threshold standard bases decisions on whether a parental choice threatens the health and safety of the child [10–12]. Many clinicians probably use a form of this standard to identify the borders of unacceptable decision making.

When parents appear to choose unacceptable treatments, clinicians should consult with colleagues to assess the acceptability of the decision and, if necessary and appropriate, to participate in the discussion. Seek to resolve disagreements without resorting to legal intervention. But the state has an interest in protecting those who cannot protect themselves. If other options have failed, clinicians should initiate an evaluation if they believe parents to be choosing unacceptable treatments.

Informed assent: the role of the child

Children should participate in decision making to the extent their development permits [7]. Decision-making capacity for children is based on the ability to understand and recall the information, to reason, which includes evaluating the risks and benefits of the options presented, to appreciate the effect of the decision on themselves, which requires advance abstract thinking, and to make a choice. Neurobiological evidence suggests that these abilities change with age and experience and are frequently present by the age of 12 [13].

For children between the ages of 7 and 11, clinicians should seek both informed permission from the parent and assent and participatory decision making from the child. Common decisions in which children participate include whether a 6-year-old wants sedation prior to an inhalation induction, whether a 10-year-old wants inhalation or intravenous induction of anesthesia, and whether an 11-year-old wants a peripheral nerve catheter for postoperative analgesia.

Clinicians should assume that adolescents 12 years and older have sufficient decision-making capacity to fulfill the ethical obligations of informed consent. Their decision-making capacities are affected, however, by their personality,

the situation, emotional impulsiveness, and a tendency to undervalue long-term consequences. The tendency to take risks increases in emotional situations. For these reasons, the influence an adolescent has on decision making is tempered by the adolescent's maturity and the risks of the decision. Decisions are considered higher risk when they include an increased likelihood of permanently lost opportunities that have noteworthy consequences. For example, delayed scoliosis surgery may increase the extent of the curve, subsequently impairing cardiopulmonary function. These impairments can affect the quality of life, future morbidity, and lifespan. In determining the extent of risk in a decision, the quality and relevance of the data must be rigorously considered.

Emancipated minors and the mature minor doctrine

Emancipated minors are minors who have a statutory right to legally consent for their own healthcare decisions. States often award this status to patients who are in the military, who are married, who have children, and who are economically independent. To be declared a mature minor, the patient must be determined by a judge to be legally and ethically capable of giving legal consent in a specific situation. Judges consider mature minor status based on the extent of the risk in the decision and the developmental maturity and age of the child.

Disclosure

The legal standard for most of the United States is the reasonable person standard, which declares that the information disclosed should satisfy the hypothetical reasonable person.

It is ethically, morally, and legally unclear as to what satisfies the reasonable person standard for informed consent for pediatric anesthesia. Children and families differ about the type and depth of information they want to receive, their desire to participate in making decisions, and their goals of the informed consent discussion [14]. For example, some want information to make decisions, some want information because they feel obligated to be informed, or some want reassurances that everything will go well, which often results in wanting less information. Sociodemographic characteristics do not reliably predict preferences for disclosure and decision making. These preferences may change given the surgery, stress, and other factors present that day.

A better approach is for the clinician to communicate only the necessary information based on the child's medical status, the risks of the procedure, and the availability of acceptable clinical options, and then seek to meet the informational and decision-making needs of the child and family by asking if they want to know more [15]. This does not burden those tepid about further information while meeting the needs of those who seek a more complete discussion. Patient-driven interactions likely reduce malpractice lawsuits. The likelihood of being sued based on informed consent malpractice issues is very rare. But the improved satisfaction that comes from patient-driven interactions (or, more simply, from listening to and responding to the decision makers' needs and requests) leads to decreased complaints and lawsuits in general [16].

Postoperative nausea and vomiting (PONV) is an archetype of the issues clinicians may want to routinely communicate

unless explicitly deferred. PONV is: (1) of great concern to parents; (2) addressable by early use of medications; (3) modifiable by behavioral and eating strategies; and (4) relevant to seeking postoperative medical interventions. Yet, in one study, PONV was discussed in only 36% of preoperative discussions [17].

The literature varies in what must be told to patients and is rarely prescriptive [18]. Practices vary, even within the same institution. For example, in a 2012 observational study of consent for pediatric anesthesia, the five most commonly discussed risks per conversation were nausea and vomiting (36%), sore throat (35%), allergy (29%), hypoxia (25%), and emergence delirium (19%) [17]. Trainees discussed about three risks in each conversation as compared to attendings who discussed only one. Nearly a third of interactions used only general statements about anesthesia risk without further information about their nature, ramifications, or incidence. It is unclear whether these variations are appropriate responses to decision makers' needs or baseline variations in standards.

Adjunct techniques, like regional analgesia, require a modification of the "meet the decision makers' needs" approach. Consider extensive knee surgery in an otherwise healthy young adolescent. Because decision makers understand that general anesthesia is essential for the surgery to proceed, they may defer more thorough risk information because it will not sway their decision. But in this child, regional analgesia is an option but not a necessity. Decision makers should be aware that regional analgesia is not essential to the surgery, and, because there is a greater role for choice, decision makers should be more extensively informed about the risks and benefits.

Patients have difficulty understanding quantitative risks. Table 1.2 describes strategies for communication [19–21].

Informed refusal

Refusal of a significant recommendation requires clinicians to more fully inform decision makers about the risks, benefits, and alternatives than if the decision makers were following the recommendation. This helps ensure that decision makers are as knowledgeable as possible about the risks of selecting a less desirable path.

Children with significant decision-making capacity (perhaps around the age of 10 years but certainly by the age of 12 years) might refuse non-emergent procedures. Clinicians should respect this refusal of assent and conscientiously avoid pressuring the child. Coercing or manipulating a child into having a procedure damages the child's trust of the medical profession and impairs future cooperation with their care. Maintenance of trust is particularly important in children with chronic medical conditions.

Strategies for resolving conflicts center on maintaining communication, clarifying misunderstandings about the anesthetic and surgical experience, and decreasing the anxiety of both the child and parents. The goal is to resolve the problem without impairing the relationships among the child, parents, and clinicians. Clinicians may want to emphasize that nothing will happen without the child's approval, *but only if that is true*. Moving the discussion away from the preoperative area or letting the child dress in street clothes will often reduce stress and improve communication.

Clinicians should recognize the distinction between using pharmacologic agents to calm an anxious adolescent to enable

Table 1.2 Communicating quantitative risk to patients [19–21]

Understanding quantitative risks may help patients make decisions. Presentation is key to understanding. Consider a patient who is concerned about PONV. They want to know the relative risks of PONV in regional anesthesia (30%) versus general anesthesia (50%).										
Approach <ol style="list-style-type: none"> 1. Use language at the 8th grade level. 2. Use absolute risks and frequencies. 3. Avoid relative descriptions like “regional anesthesia decreases the rate of PONV by 50% compared to general anesthesia.” 4. Because patients have different abilities, data should be presented in a variety of ways cautiously. Too much information too quickly is confusing. 										
Verbal presentations					Analysis					
“With regional anesthesia, there is a 30% chance of PONV. With general anesthesia, there is a 50% change of PONV”					<ul style="list-style-type: none"> • Relies on an understanding of percentages that is not universally present 					
“With regional anesthesia, there is a 30% chance of PONV, which is 3 out of 10 patients. With general anesthesia, there is a 50% change of PONV, which is 5 out of 10 patients”					<ul style="list-style-type: none"> • Adds a frequency (3 out of 10 patients; 5 out of 10 patients) <ul style="list-style-type: none"> ◦ Presents a second avenue to understanding ◦ Is often easier to understand 					
“With regional anesthesia, there is a 30% chance of PONV, which is 3 out of 10 patients. With general anesthesia, there is a 50% chance of PONV, which is 5 out of 10 patients. That means that 2 more patients out of 10 will have postoperative vomiting if we use general anesthesia					<ul style="list-style-type: none"> • Adds a direct comparison using an absolute number (2 more patients out of 10), which is often helpful • Increases the language complexity • Possible solutions <ul style="list-style-type: none"> ◦ Present information in smaller chunks, which makes it easier to understand ◦ Use pictorial representation 					
Pictorial presentations					Analysis					
Pictorial representation #1					<ul style="list-style-type: none"> • Clinician can draw ten dots and fill in the appropriate number • Described as the number of patients out of 10 who will have PONV with that type of anesthesia 					
	1	2	3	4	5	6	7	8	9	10
Regional anesthesia	■	■	■	□	□	□	□	□	□	□
General anesthesia	☒	☒	☒	☒	☒	□	□	□	□	□
Pictorial representation #2					<ul style="list-style-type: none"> • One line can be used to compare two treatments • The additional patients who will have PONV can be circled or highlighted 					
	1	2	3	4	5	6	7	8	9	10
Regional anesthesia	■	■	■	☒	☒	□	□	□	□	□
General anesthesia	■	■	■	☒	☒	□	□	□	□	□

proceeding and using pharmacologic agents to manipulate the adolescent into proceeding. Consider the 15-year-old who becomes overwhelmingly anxious and refuses surgery. It would be inappropriate to unilaterally administer midazolam to gain cooperation. On the other hand, it is wholly appropriate to seek the adolescent’s assent to receive sufficient anxiolysis so they may undergo the procedure. Time, respect, and simple strategies often resolve issues satisfactorily and efficiently.

Children of Jehovah’s Witnesses

Jehovah’s Witnesses interpret biblical scripture to mean that anyone who accepts blood will be “cut off from his people” and not receive eternal salvation [22]. Adults may refuse potentially life-sustaining transfusion therapy. The presumption is that they are making an informed and voluntary decision. Courts commonly authorize necessary perioperative transfusions for children of Jehovah’s Witnesses. The courts base these decisions on the doctrine of *parens patriae*, the obligation of the state to protect the interests of incompetent patients.

Clinicians should directly address perioperative transfusion therapy when caring for a child of Jehovah’s Witnesses. The

child and family should be informed that, as with all patients, attempts will be made to follow the family’s wishes within the standard of care. Because refusal of transfusion therapy is deemed a “matter of conscience,” the clinicians should clarify acceptable interventions. Deliberate hypotension, deliberate hypothermia, and hemodilution are often acceptable techniques. Synthetic colloid solutions, dextran, erythropoietin, desmopressin, and preoperative iron are usually acceptable. Some Jehovah’s Witnesses will accept blood removed and returned in a continuous loop, such as cell saver blood. The family should be informed that in unexpected critical situations requiring transfusion, the clinician will transfuse while concomitantly or later seeking legal authorization. Clinicians should be familiar with the hospital’s preferred mechanism for obtaining legal authorization. In instances where the likelihood of requiring blood is high, or the local judiciary is not that familiar with case law for Jehovah’s Witnesses, clinicians may choose to obtain the court order preoperatively if there is a palpable likelihood of transfusion.

Elective procedures may be postponed until the child is of sufficient age and maturity to decide about transfusion therapy. But delays may increase the risk of morbidity or the quality of outcome. Factors affecting whether to proceed

include the quantitative and qualitative changes in risks and benefits.

Reasonable people disagree as to whether clinicians should change their transfusion triggers for a child of a Jehovah's Witness. On one hand, when to transfuse is often a judgment call, affected by the child's baseline health, clinical findings, lab values, expectation of future blood loss, knowledge of surgeon and procedure, risk tolerance, and gestalt. Given that, it may be reasonable to transfuse later than normal. On the other hand, although clinicians acknowledge transfusion triggers vary, they presumably transfuse only when necessary. In this analysis, changing transfusion triggers provides less optimal care, which is inconsistent with the obligation to treat the child of a Jehovah's Witness like any other child.

When an adolescent wishes to refuse perioperative transfusion, the minor needs to articulate sufficiently mature reasons, be properly engaged with the religion, and understand ramifications to self and family about possible outcomes. A private conversation is necessary to assess for coercion or manipulation. Ethics consultations are particularly useful in making these determinations. When brought to court, judges often determine whether adolescents may refuse transfusion by the likelihood of significant benefits like 5-year survival and the practicality of initiating and maintaining transfusion therapy. Children as young as 14 have been given the right to decline transfusion therapy, even when they had a high probability of 5-year survival.

When arrangements are made to honor an adolescent's preferences to refuse transfusion, plans must be made to ensure other perioperative and postoperative clinicians are willing to honor the agreements, as well as to ensure a plan is in place to honor the agreement in case the child needs to return to the operating room urgently.

Emergency care

Emergency therapy is considered desirable and should be given to the minor who does not have a parent available to give legal consent or informed permission [23]. Clinicians should err on the side of treating if they are unsure whether to wait for parental consent.

Emergency therapy becomes more complex when adolescents nearing the age of majority refuse to assent to care. Urgency may not permit the extended evaluation necessary to determine whether the minor has sufficient decision-making capacity. Clinicians should use the best interest standard to guide therapy acutely. Consider a 15-year-old with an acute cervical fracture who refuses emergency stabilization. Forgoing cervical stabilization may cause irrevocable harm. The typical adolescent's decidedly short-term outlook and overvaluation of physical abilities make it unlikely that the adolescent possesses sufficient decision-making capacity in the acute situation. It is hard to imagine honoring an adolescent's refusal of emergent therapy in this case.

The temporarily impaired parent

Chemically intoxicated parents may be disruptive, dangerous, and incapable of fulfilling surrogate responsibilities. Clinicians should use the least restrictive means to protect patient and parent confidentiality while ensuring the safety of the child, the impaired parent, and others present.

Although it seems ethically and legally prudent to postpone routine treatment until informed permission and legal consent can be obtained from an unimpaired parent, clinicians should weigh the benefits of postponement with the risk that impaired parents may not reliably return. It may be in the child's best interests to proceed with a routine procedure even though the impaired parent is unable to give informed permission and legal consent. Consultation with legal, risk management, and ethics colleagues may help.

Consent for pediatric procedures without direct benefits

Pediatric clinicians may encounter children undergoing bone marrow donation for siblings who would benefit from hematopoietic stem cell transplantation [24]. The stem cell donor receives no direct medical benefit from the donation. The major risks of donation are the anesthetic and the potential need for transfusion.

The benefit of donation is commonly considered to be the psychosocial benefit of helping a family member. Pediatric donors report that the benefits of donations outweigh the physical harm [25]. As can be expected in such a complex dynamic, however, donation can result in moderate post-traumatic stress. Some donors felt they did not have a choice about being a donor and that they may be responsible for unsuccessful transplants.

Given the risks and benefits and the unique position of families in society, the American Academy of Pediatrics believes it is ethically permissible for minors to donate bone marrow when certain requirements are met, including a close relationship between donor and recipient, considerations of the risks of bone marrow donation, a likelihood of benefit to the recipient, and an absence of a suitable medically equivalent adult relative. Parental consent and patient assent is needed. Independent advocates for potential donors have been used to minimize the potential for inappropriate parental influence [26].

Genetic testing and biobanking

While genetic testing can provide the substantial benefits of confirming a diagnosis, determining carrier status, or testing for disorders of late onset, it can also harm by informing people about their genetic lineage without their consent or adequate preparation.

Whether to test is particularly hazardous with children. Genetic testing may affect personal psychosocial development and business and insurance opportunities and removes the opportunity to choose whether to obtain that genetic information. Testing should be performed only when there are immediate medical benefits to the child or when there are medical benefits to a family member and no expected harm to the child. Otherwise, testing should be deferred until the child can display an understanding of the consequences of genetic testing.

Consent for biobanking, the keeping of tissues for genetic research, is problematic, assuming that the revisions to the more than 25-year-old Common Rule begin as expected in 2018. The Common Rule is the core ethics regulations governing human research in the United States. The revision permits

using broad consent for biobanking [27,28]. Within some limitations, broad consent permits the use of tissues without additional permission from the donor [29]. One of the problems with broad consent is that donors or their surrogates may be consenting to unknown unimaginable risks [29]. No matter the protections, privacy is always at risk [30]. Consequences can include denial of life insurance, and, potentially in the future as health insurance laws change, denial or exorbitant premiums for health insurance.

Children should be involved in the consent process for biobanking to the developmentally appropriate extent [31]. The issues of consent change when the child reaches adulthood. One potential solution is to require biobanks to contact donors when they reach adulthood to either require the now adult to opt in for biobanking or provide the opportunity to opt out. This is not being done routinely [32].

KEY POINTS: THE INFORMED CONSENT PROCESS FOR CHILDREN

- Respect the “experience, perspective, and power of children” [8]. Legitimately involve children to the developmentally appropriate extent. Avoid pro forma solicitations
- Prioritize meeting the child and family’s informational, decision-making, and emotional needs during the informed consent process
- Use verbal and pictorial strategies to quantify risks
- Under certain circumstances, adolescents may refuse potentially life-sustaining transfusion therapy for religious reasons
- Genetic testing and biobanking can lead to unforeseen consequences for the donor and their relatives

Forgoing potentially life-sustaining treatment

Children, like adults, have the right to limit LSMT when the likelihood and quality of potential burdens outweigh the likelihood and quality of potential benefits, as defined by the child and family [33]. Benefits include a prolonged acceptable quality of life. Burdens include intractable pain, disability, emotional suffering, or effects that diminish the child’s quality of life.

The term “life-sustaining medical treatment” is preferred to the older term “do not resuscitate” to emphasize that treatment preferences range along a continuum instead of being binary. “Potentially” acknowledges the uncertain effectiveness of the treatments.

Perioperative limitations on potentially life-sustaining treatment

Limiting perioperative potentially LSMT allows children to have an opportunity to receive beneficial therapy without being forced to accept unwanted burdens [33,34]. Treatments may include procedures that increase quality of life, enable living at home, improve ability to interact, improve pain

management, decrease pain, and treat non-terminal problems or urgent problems unrelated to the primary problem. Potential burdens from procedures may arise from resuscitation attempts, post-resuscitation medical care, or resultant functional or cognitive decrements. These burdens may make further resuscitation or intensive care therapy not “worth it.” Considering both short- and long-term potential benefits and burdens helps clinicians understand the child’s perspective, which improves honoring preferences.

The American Society of Anesthesiologists, the American Academy of Pediatrics, and the American College of Surgeons mandate reconsideration of existing limitations on LSMT before going to the operating room or procedure area.

Reconsidering the order prior to surgery requires clarifying the goals for the procedure and end-of-life care through discussions with the child, parents, and relevant clinicians such as surgeons and primary care physicians. Children should be involved in a developmentally appropriate manner. In practice, the reconsideration of LSMT for the perioperative period should result in either full resuscitation or a goal-directed approach toward perioperative resuscitation.

Goal-directed approaches permit decision makers to guide therapy by prioritizing outcomes (e.g. “I don’t want to suffer in the ICU for two weeks before I die.”) rather than specific therapies (e.g. cardiopulmonary resuscitation) [35]. Clinicians can guide the discussion by exploring acceptable burdens, desirable benefits, and the likelihood of the ranges of outcomes. Clinicians should explain the differences between ward and operating room resuscitation, emphasizing the idea that a dedicated clinician with understanding of the end-of-life goals and the ability to make a real-time assessment of the clinical problem as well as the ability to institute treatment immediately will be present throughout. Box 1.2 lists additional information to include in the discussion.

Operating room clinicians use their clinical judgment to determine whether and to what extent resuscitation will help achieve these goals. The decision about whether to use a certain intervention, such as chest compressions, will likely be more consistent with the end-of-life goals if the decision to

Box 1.2: Components of the discussion for perioperative limitations on potentially life-sustaining medical treatment (LSMT) [33–35]

- Planned procedure and anticipated benefit to child
- Description of advantages of perioperative LSMT as compared to ward LSMT
- Likelihood of requiring resuscitation
- Reversibility of likely causes that require resuscitation
- Description of potential interventions and their consequences
- Chances of successful resuscitation including differences between outcomes to witnessed and unwitnessed arrests
- Ranges of outcomes with and without resuscitation
- Responses to iatrogenic events
- Intended and possible venues and types of postoperative care
- Use of postoperative trials of therapy
- Postoperative timing and mechanisms for reinstitution of previous limitations of LSMT
- Establishment of an agreement through a goal-directed approach or revocation of the do-not-resuscitate order for the perioperative period
- Documentation

institute is made when the etiology of the event is known. This model encourages the ethically redoubtable strategy of trialing therapies. A trial of chest compressions that do not achieve specific goals provides evidence that continuing the therapy would be inconsistent with the goals of end-of-life care. Witnessed arrests in the operating room often have a better outcome than unwitnessed arrests due to the more immediate intervention and the greater likelihood that the cause of the arrest is known.

Most decision makers choose to use a goal-directed approach that authorizes temporary therapeutic interventions to manage quickly and easily reversible events, but reject those interventions that will likely result in permanent sequelae, such as neurologic impairment, from receiving potentially LSMT. For example, a brief bradyarrhythmia that responds to intravenous epinephrine and chest compressions would be consistent with the authorization to treat events that are temporary, easily reversible, and unlikely to have significant sequelae. On the other hand, if the bradyarrhythmia resulted in an extended resuscitation, continued therapy would require unacceptable burdens that in any case would be unlikely to achieve the patient's return to previous functional status. In that case, it would be appropriate to cease resuscitation efforts.

This common goal-directed preference can be documented as "The patient desires resuscitative efforts during surgery (and in the postanesthesia care unit (PACU)) only if the adverse events are believed to be both temporary and reversible in the clinical judgment of the attending anesthesiologists and surgeons."

The goal-directed approach requires determining when the child returns to their previous status for LSMT. Given that the goal-directed approach requires intimate knowledge and that it is intended to respond to the vicissitudes of anesthesia and surgery, the perioperative agreement is often discontinued when the patient is discharged from the PACU.

Clinicians should also discuss whether to try a postoperative trial of therapy before concluding that the burdens of continuing therapy outweigh the benefits. A trial of therapy allows decision makers and clinicians to determine how well a treatment achieves a defined agreed-upon goal, rather than presuming whether the therapy would work [3]. Trials may be limited by time or other factors. Trials permit children to tolerate a relatively small amount of burden, such as brief mechanical ventilation, to see if it would accomplish their defined goals. This information guides further decision making with greater certainty of burdens and benefits.

In pediatrics, precisely defining and documenting postoperative plans is often less essential, because parents are often available in the postoperative period to make decisions regarding therapy. Parents are often cognitively capable of participating in discussions of withdrawal of therapy because they have already grappled with analyzing the benefits and burdens of end-of-life care. The presence of parents permits greater trials of perioperative resuscitation while still respecting the decision to limit the burdens. However, developmentally appropriate conversations with the patient are essential when a child is able to participate in these discussions. A child's preferences should be incorporated into decision making similar to obtaining assent.

Resist the hegemonic instinct to overreact to iatrogenic events. Decision makers chose to limit care because they do not want the burden of undesirable outcomes. Iatrogenic issues do not supersede agreed-upon preferences for limitations on potentially LSMT unless knowledge of the event makes the associated burdens and benefits of treatment consistent with the agreed-upon plan.

That said, putting aside personal feelings about an iatrogenic event is hard. But children and families care about how they are, not how they got there.

Physician orders for life-sustaining treatment

A physician order for life-sustaining treatment (POLST) promotes the honoring of resuscitation preferences by giving the preferences the power of a physician order. This order is valid across in- and out-of-hospital locations [36]. As compared to other advance directives, which can be prepared without professional medical guidance, POLSTs ensure the advice of a physician on how to achieve end-of-life care preferences. POLSTs document preferences for LSMT, other medical interventions, and management of artificial nutrition [37]. POLST documents appear to improve communication and honoring of preferences, particularly across settings [38–40].

Perhaps the biggest impediment to POLSTs is physician unfamiliarity [41]. From the perioperative clinician's point of view, it should be taken as if the child has a duly authorized limitation of LSMT. It should thus undergo required reconsideration.

Barriers to honoring perioperative limitations on life-sustaining treatment

Although honoring limitations on LSMT is improving in the main, clinicians still poorly honor end-of-life care preferences [36,42,43]. Clinicians remain inadequately informed about policies, law, and ethics, hindered by sabotaging systems and poisoned by lore and misinformation [44–48].

Insufficient early identification and communication about a child who needs a perioperative reconsideration of LSMT, such as one with a POLST, limits the ability to find the right clinicians, have a robust discussion, and reach an agreement satisfactory to the child, family, and clinicians. Children having minor surgery or those who have not had a preoperative visit are more likely to remain unidentified until the day of surgery.

Lore and break room gossip reinforce the incorrect perception that honoring perioperative limitations on LSMT may result in being sued [49]. Statutes that address requirements for limitations on LSMT often include immunity provisions that protect clinicians from liability. Given the right of children to avoid inappropriate treatment, and the lack of judgments against clinicians who honor properly documented LSMT, the risk of honoring limitations on LSMT is likely to be lower than the risk of not honoring it.

Barriers that are less obvious include the natural desire to avoid most risk, particularly what is incorrectly perceived as a significant risk for little benefit [49]. Many clinicians like to avoid ambiguous situations in which they

have little experience making judgments and in which they are more prone to private or public criticism. These concerns can lead to anticipatory regret, letting an uninformed or overactive imagination create a fictional horrifying outcome that makes honoring limitations too risky. Clinicians overcome these honest but inappropriate feelings by reality testing with experts, seeking to become more skilled in these areas, and remembering that clinicians serve patients.

Potentially inappropriate interventions

Most of the confusion surrounding the concept of futility comes from imprecise terminology. Futile therapy should be viewed as treatments that cannot accomplish a specific physiological goal. In that sense, dilemmas about whether to use futile therapy rarely arise. Interventions with a low likelihood of success, on the other hand, may be considered potentially inappropriate but they cannot be considered futile. An intervention may be considered potentially inappropriate if there is “no reasonable expectation” that a significant defined endpoint will be reached, the burdens to the child, feasibility, or, at times, cost [50].

At the clinician level, discussions about inappropriate interventions center on the benefits and burdens to the child. Qualitative and quantitative considerations should be defined carefully and clinicians should explain whether the information used to form the estimation is based upon intuition, clinical experience, or rigorous and sufficiently relevant scientific studies. Complicating matters is the dubiety in predicting the likelihood and range of outcomes of therapeutic interventions in very young children. In the end, in the absence of national standards, decision making for a child regarding inappropriate care should be based on the benefits and burdens on the child and not on cost [51]. Hospitals should have established processes for resolving conflicts [52].

Perioperative clinicians encounter cases that seem to be inappropriate treatments. Aside from differences in core values and beliefs, parents have other influences that encourage them to seek seemingly inappropriate care (Box 1.3). Understanding these factors helps clinicians be empathetic.

What would you do in my situation?

Parents may ask clinicians what they would do in the same situation. Clinicians should attempt to determine what the parent is asking before directly answering this question.

If they are asking for help making a decision, either because of difficulty managing the complexity of information or because of uncertainty, it is important to clarify the goals or values of the parents. Clinicians can then answer the question, “If that were my goal, I would do this, because....” Explaining why allows parents to apply their own values to the reasoning.

If parents are unsure about how to weigh competing values, it is appropriate for clinicians to share their values, with the caveat that many other approaches are acceptable and that the parents’ values take priority. Clinicians can explain that to parents: “My job is to help you make one of the several

Box 1.3: Why are we doing this case? Factors that affect parental desire to seek seemingly inappropriate care

Parents seek seemingly inappropriate care for personal, familial, and societal reasons. These latent factors influence decision making.

- Unrealistic expectations about prognosis or effectiveness of treatment
 - Previously incorrect prognoses about their child (“Won’t live past age 2”)
 - Local rumors about “miraculous” cures
 - Public stories about “miraculous” cures
- Influence/disapproval from insufficiently informed family
 - Fear of damaging personal reputation in their community
 - Fear of subtle ostracism
 - Internal or external pressure not to damage family reputation
- Guilt
 - Responsible for previous actions (e.g. left with “irresponsible” relative)
 - Responsible for “delaying” treatment because they “missed” something
 - Vague but wholly wrong feeling that it was their fault
 - Emotional overtones of “causing death”
- Mistrust of clinicians, hospitals, or medical systems
 - Personal disturbing individual interactions
 - Legitimate and illegitimate stories and events engendering distrust
 - Coming from communities that have experienced organizational prejudice (e.g. racial, gender, ethnic, socioeconomic, etc.)
- Inadequate education/guidance from clinicians
 - No clearly identified clinician coordinating care
 - Inadequate communication among clinicians
 - No process to address LSMT with family
 - Breakdown of communication among family and clinicians
 - Well-meaning but poorly considered comment by a peripheral clinician (sometimes medical student) on to which families latch

LSMT, life-sustaining medical treatment.

reasonable choices that fits your values. Let’s discuss how we can apply your values to this decision.”

If parents are looking for reassurance for a reasonable decision that is not the one the clinician would have chosen, clinicians can respond by affirming both the appropriateness of the decision and the naturalness of feeling uncertain [53]. Admitting uncertainty about the “right” thing to do confirms to the parents the difficulty of the decision.

Organ procurement after cardiac death

In organ procurement after death by neurological criteria, the child is declared dead before going to the operating room. In organ procurement after cardiac (or circulatory) death (DCD), a child in whom the decision has been made to withdraw potentially LSMT is brought to the operating room and then treatment is withdrawn. If the child is declared dead by cardiac status within a pre-established time, organ procurement proceeds. Although widely accepted, concerns about DCD include whether the dying process is altered by interventions to facilitate organ procurement. See Chapter 30 for more information about organ donation after cardiac death.

KEY POINTS: FORGOING POTENTIALLY LIFE-SUSTAINING TREATMENT

- Children have the same right as adults to limit potentially LSMT, but predictions about the likelihoods and range of outcomes are less reliable
- Orders for limitations for LSMT must be reconsidered for the perioperative period. They may be honored under a goal-directed approach
- Trials of therapy increase the likelihood of honoring preferences for end-of-life care. Trials allow decision makers to test the assumption that a treatment may achieve specific goals while permitting it to be withdrawn if the treatment becomes too burdensome
- Desires for what appear to be inappropriate treatment come from values, beliefs, perceptions, personal experience, and community history
- Work with children and families to apply their values to decision making

Special circumstances in pediatric anesthesia

Research in pediatric patients

The anesthesiologist Henry K. Beecher was one of the first to recognize that research in pediatric patients requires greater oversight than research in adults [54]. Research subjects requiring surrogate consent are vulnerable to abuse. Pediatric research exposes children to unknown risks of long-term harm because research interventions occur during growth and development of the child [55].

The increased risk of harm and lack of direct benefit to the child increase the obligation to obtain the developmentally appropriate assent from the child. This obligation is not always met, particularly in diseases that have a strong emotional overlay, like cancer [56,57]. Assent may be waived if there is the prospect of direct benefit to the child that is available only through participation in research. Although undesirable, assent also may be waived if the study exposes the child to no more than minimal risks or if the study could not sensibly proceed without the waiver [50,51].

Federal guidelines define four categories of pediatric research (Box 1.4). The hallmark of these categories is that potential benefits must increase commensurate with potential risks. Most controversy about pediatric research concerns the interpretations of minimal risk and minor increase over minimal risk [52].

Minimal risk is defined as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests” [58,59].

The common interpretation is that minimal risk refers to risks encountered by healthy children in a safe environment, such as playing sports and riding in a car [59,60]. A previous competing interpretation, now out of favor, used the more relative interpretation of basing the standard of “daily life” on the events to which children enrolled in the research are

Box 1.4: Federal classifications for pediatric research [50]

1. Research not involving greater than minimal risk.
 - a. IRB determines minimal risk
 - b. IRB finds and documents that adequate provisions are made for soliciting assent from children and permission from one of their parents
2. Research involving greater than minimal risk but presenting the prospect of direct benefit to the individual subjects.
 - a. IRB justifies the risk by the anticipated benefit to the subjects
 - b. The relation of the anticipated benefit to the risk is at least as favorable as that presented by available alternative approaches
 - c. Adequate provisions for assent and permission from one of the parents
3. Research involving greater than minimal risk and no prospect of direct benefit to individual subjects, but likely to yield generalizable knowledge about the subject’s disorder or condition (commonly known as “minor increase over minimal risk”).
 - a. IRB determines the risk represents a minor increase over minimal risk
 - b. The intervention or procedure presents experiences to subjects that are reasonably commensurate with those inherent in their actual or expected medical, dental, psychological, social, or educational situations
 - c. The intervention or procedure is likely to yield generalizable knowledge ... which is of vital importance for the understanding or amelioration of subject’s disorder or condition
 - d. Adequate provisions for assent and permission from both of the parents
4. Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children.

IRB, institutional review board.

routinely exposed. In other words, if a child enrolled in the study routinely receives lumbar punctures as part of therapy, then it may be acceptable to expose a child to the risk of a lumbar puncture for study purposes.

The category “*greater than minimal risk* and no prospect of direct benefit to individual subjects, but likely to yield generalizable knowledge about the subject’s disorder or condition ... which is of vital importance” defines when it is acceptable to expose a child to what is called “*minor increase over minimal risk*” [58]. “*Minor increase over minimal risk*” has been interpreted as pain, discomfort, or stress that is transient, reversible, and not severe [61]. Risk assessment is based on the combined exposure to risks throughout the study and the relationship between the risks and the patient population. For example, although drawing blood in healthy 15-year-olds may be considered acceptable, drawing blood from 15-year-olds with severe autism spectrum disorder may be unacceptable because their inability to understand may cause intolerable stress [62].

“*Condition*” is used to mean characteristics “that an established body of scientific or clinical evidence has shown to negatively affect children’s health and wellbeing or to increase the risk of developing a health problem in the future” [62]. For example, consider a protocol to assess insulin resistance in obese children who do not have type 2 diabetes. If the investigator presented sufficient scientific support to the institutional review board that obese children are at increased risk of developing diabetes because of their obesity, then those obese

children would be acceptable research subjects for this study. Svelte children would not be acceptable, because they would not be considered at risk for developing diabetes.

Stringent regulations certainly hinder necessary and beneficial research [56,57]. But regulations are often responses to previous transgressions. At some point, relaxation of regulations will reanimate the abuses that beget the regulations. It is difficult to identify that line until it is crossed.

Improving the institutional review board (IRB) process may minimize the inaccurate estimations of risk that hinder appropriate research and permit inappropriate research. An individual's intuition about the risk level of an activity is hampered by cognitive biases, such as familiarity, control of activity, and reversibility of the potential harms [63]. Systematizing evaluation of research risks may reduce inaccurate estimations of risk. One approach is to use a standardized scale to categorize the extent and likelihood of each potential harm and then compare the potential harms with comparative activities [64].

Socioeconomically disadvantaged children are overrepresented in clinical research [65]. Their environments may drive or worsen diseases such as reactive airway disease, and most research is performed in urban hospitals. Children in more economically settled situations get the benefit of the research without bearing proportionate risk. In addition, socioeconomically disadvantaged children and families may be more enticed to participate in research because of the commonly offered relatively inexpensive tokens of gratitude. But to socioeconomically disadvantaged families, what the researcher or IRB perceives as a minor gift can be a strong incentive to participate. See Chapter 4 for additional discussion about research consent and ethics.

Confidentiality for adolescents

Open discussion, the lynchpin to a successful adolescent–clinician relationship, occurs only when the adolescent believes in the openness and confidentiality of the discussion [66,67]. Confidentiality means the adolescent owns their information, and, as such, it may not be shared without the adolescent's permission [68]. The adolescent's emerging desire for autonomy and their cognitive decision-making abilities make them developmentally ready for this responsibility.

Clinicians are obligated to protect patient information from unauthorized and unnecessary disclosure. With adolescents, confidentiality is crucial for even the anodyne. Adolescents concerned about confidentiality withhold pertinent information and defer necessary treatment [66,67,69]. Clinicians may want to ask sensitive questions without the parents present. Squarely addressing confidentiality concerns often improves truthfulness.

But adolescent confidentiality is not absolute. Honoring an adolescent's preferences for autonomy may compete with the obligation to ensure the adolescent is making a reasonable decision. It is ethically justifiable to breach confidentiality only when complying with reporting statutes or when breaching confidentiality will prevent serious harm to the child or another. These decisions are not obvious, and clinicians should use patient, family, and case characteristics in consultation with ethics or legal consultations to determine the appropriateness of breaching confidentiality.

Confidentiality breaches occur by sloppy and insecure use of medical records and electronic communications, by discussing patients in front of other patients or uninvolved clinicians in public areas like elevators, hallways, and cafeterias, and by clinicians being forced to have public discussions with patients or families because of inadequate private facilities, such as in the family waiting room. The most common breaches were to clinicians uninvolved in patient care about patients' sexual activities, mental or other stigmatizing illnesses, and racial or ethnic backgrounds [70].

The pregnant adolescent

Hospitals and clinicians should have a defined approach to the preoperative adolescent who has a positive pregnancy test. As described previously, this information is the adolescent's and should only be shared with the patient's permission. State statutes may limit clinicians to informing only the adolescent about a positive pregnancy test [71,72]. In addition to ethical principles and practical reasons, these statutes are specifically present to address concerns about child abuse in pregnant adolescents.

Clinicians in possession of sensitive information should encourage the adolescent to share the relevant information with the parents. Involving adolescent specialists or social workers may facilitate communicating with the parents and receiving future care.

The ethical complexity increases logarithmically when pregnant adolescents do not want to inform their parents and it is appropriate to postpone the procedure [73]. Even though clinicians must postpone the case in a manner that does not breach confidentiality, the details of how the postponement is communicated affect the ability to maintain confidentiality. For example, clinicians can issue a terse communiqué to the parents that the procedure will be postponed. While this approach avoids explicit lying, its oddness may confuse parents and trigger a cascade of questions leading to a loss of confidentiality. On the other hand, clinicians may actively deceive, correctly reasoning that because parents have no right to that information, their primary obligation is to preserve confidentiality.

Albeit peculiar in a medical textbook, perhaps a short course in deception is useful [74,75]. Clinicians should try to avoid deception. But, when necessary, as a later resort to maintain confidentiality, it may be the least objectionable approach. It is perhaps easier to mitigate the sting of being deceptive by considering that, ethically, only the patient has the right to that information, and you are doing what is practically necessary to maintain confidentiality.

Clinicians should deceive in ways that will be successful, not require diagnostic or therapeutic interventions, and not unduly worry parents. For example, while intimating about unavailable operating room space and emergency surgeries may be useful, the excuse is rather weak if stated in the morning, when the family could offer to wait until one is available. Using a "new murmur" as an excuse may worry parents and cause unnecessary consultations. More simple deceits, such as postponement due to concerns about inadequate fasting or upper respiratory infections, tend to minimize unintended consequences.

The American Academy of Pediatrics supports confidentiality for adolescents seeking information about having an abortion [76]. Unless restricted by state law, adolescents may have abortions without parental consent. The rules surrounding parental involvement in elective abortions vary by state [71]. States may require either parental consent or notification prior to an elective abortion [71]. To ensure that adolescents can seek an abortion confidentially in states with parental involvement laws, states must have a judicial bypass procedure to preclude parental involvement. In a judicial bypass hearing, the judge interviews the adolescent to determine sufficient maturity to consent for an abortion. Even if the judge determines the adolescent insufficiently mature, the judge may grant permission for the abortion if the judge believes it is in the adolescent's best interest.

LGBTQI+ patients

Although the number of LGBTQI+ adolescents and the incidence of gender dysphoria are increasing, the specialization of care for these individuals means there is often clinical inexperience. LGBTQI (lesbian, gay, bisexual, transgender, transsexual, queer, intersex) is an insufficient term to describe the variations of preferences for gender identification or no identification. A person's genetic biology is called sex. Gender is a self-identified social construct of how a person presents themselves to those around them. Gender identification is unconstrained, and includes no gender, gender fluid and combined or unnamed genders. Because covering the spectrum would be unwieldy, the "+" is to indicate those unmentioned, without prejudice.

The wholly legitimate issue of gender variation or dysphoria in the prepubescent child is widely misunderstood and not infrequently grotesquely mocked. Different treatments are appropriate. Decisions about more definitive interventions are usually postponed until puberty, given the uncertain natural history [77]. Clinicians must be supportive in following the chosen treatment (e.g. support for gender transition) for their patient.

Being an adolescent is hard. Isolation, prejudice, and even implicit or explicit condemnation from parents and other family make the difficulty of being an LGBTQI+ adolescent unimaginable for those who have not had the experience. Because of these factors, LGBTQI+ children have higher rates of substance abuse, homelessness, suicidal ideation, and physical harm. Reprinted rather widely is part of the 2015 suicide note of Leelay Alcorn, who self-identified as transgender. This note exemplifies the isolation, shame, and pain. "Please don't be sad, it's for the better. The life I would've have lived isn't worth living in... because I'm transgender...I never told anyone and I just continued to do traditionally 'boyish' things to try to fit in." [78].

Clinicians should avoid heteronormative assumptions (asking if someone has a boyfriend or a girlfriend), identify preferred name (often incorrectly identified on records if the name has not been legally changed), identify preferred pronouns or use non-gender pronouns, although in conversation with children their name should be used, articulate the purpose of potentially awkward questions, and use genderless language.

KEY POINTS: SPECIAL CIRCUMSTANCES IN PEDIATRIC ANESTHESIA

- Adolescents deserve confidentiality for ethical and practical reasons. Clinicians are responsible for maintaining appropriate confidentiality
- Diligently assess yourself for personal but unintended behaviors that may lead to health or healthcare disparities, particularly across race, gender, and socioeconomic status. Develop strategies to minimize these actions
- Be cautious about seemingly innocuous language that makes presumptions that may hurt or shame adolescents

Professionalism in pediatric anesthesia

Advocacy and good citizenship

Physicians owe their ability to train, practice, and thrive to society's largesse. The implicit social contract therefore obligates physicians to manage matters within their sphere of influence, with a special obligation to address issues that "directly influence individuals' health" in the physician's community [79,80]. Community may refer to a physical location or a type of patient to whom the physician is particularly obligated. Pediatric anesthesiologists have a special obligation to further pediatric healthcare [81,82].

Pediatric anesthesiologists fulfill obligations to society by participating in activities that are consistent with the individual's "expertise, interests and situations" (Fig. 1.1) [80]. Pediatric clinicians in particular should address the healthcare disparities of quality of care and access to care seen across socioeconomic, racial, gender, geographical, and other cohorts that lead to the health disparities in morbidity and mortality [83,84].

Safety and quality care initiatives

Clinicians must work to improve safety. Clinically, clinicians need to actively support safety initiatives that seek to improve care such as the procedural time out and the Clean Hands Count initiative. Ignoring or bypassing inefficient, impractical, or harmful policies prevents developing a functional policy and leads to a dysfunctional culture of clinicians choosing which rules to follow [85]. Clinicians need to bring unsuccessful policies to leadership, who must be willing to honestly discuss and address concerns without blaming clinicians or demeaning them by declaring "try harder." Even one brush-off by leadership will chill future communication from the front lines.

Clinicians should do their best to improve care by reporting near misses or other potential risks. Clinicians are suspicious (sometimes rightly) of the trumpeted "blame free" approach to reporting potential errors or near misses [86]. To fulfill professional obligations of identifying potential risks, suspicious clinicians should reality test their perception or find a different way to highlight the risk. System flaws that lead to medical errors can only be identified by honest reporting and by participating in root cause analyses.

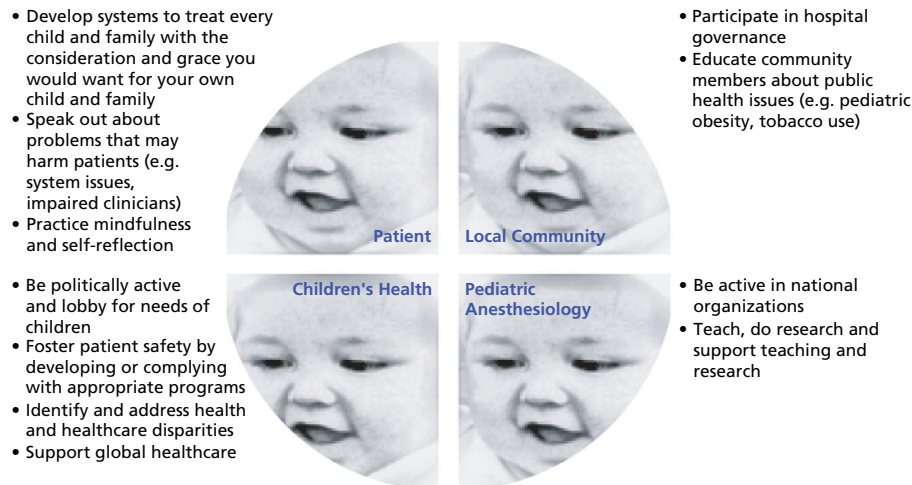


Figure 1.1 Obligations of pediatric anesthesiologists. Pediatric anesthesiologists are obligated to these four communities. Individual anesthesiologists are not expected to fulfill every obligation. “Units” of anesthesiologists such as private practice groups, academic departments, and state societies should fulfill these obligations collectively. A few examples are given.

Disclosure and apology

Although viscerally seductive, hiding medical errors violates informed consent principles, destroys trust when the error is inevitably revealed, and leads to legal action [87]. To be sure, it is understandable to want to hide a medical error. Clinicians foresee mercurial treatment by the hospital or legal system, do not receive adequate psychosocial support, and are inadequately educated about how to manage these conversations [88].

Children and parents wish to be informed about medical errors. Proper disclosure and apology can improve trust, communication, and respect and may give them a greater sense of control, which some research suggests may lead to better outcomes [89]. They also wish to receive appropriate apologies, even if it makes them more anxious.

Thoughtful full disclosure should commence upon recognition of the problem. Wise clinicians unskilled in disclosure and apology involve an expert. The expert can prepare clinicians by rehearsing process and content and by providing support for the clinician. The expert can arrange for continuing communication and provide emotional support for the family. Clinicians who make errors, sometimes referred to as “second victims” [90], may be understandably rattled and may not be able to provide emotional support. Clinicians should share what is known as quickly as reasonably possible, but they should not make assumptions about what is not known, particularly about fault. Decision makers should be informed about the medical implications of the event and any necessary treatment. Because disclosure is a process over time, the child and family should be given a contact person skilled in disclosure and apology who will be available to answer questions, arrange meetings, explain the results of the investigation, and describe plans to prevent comparable events.

Most arguments against apology about and disclosure of errors center on increasing the risk of being successfully sued and on protecting the patient from unnecessary anxiety regarding the event or future care. Upon examination, these arguments are weak. An apology is an expression of regret or sorrow. A sincere apology followed by actions consistent

with regret is invaluable; an insincere apology is costly. Even though more than half the states have laws prohibiting the admission of apology or sympathy as evidence of wrongdoing, it is conceivable that an apology may increase the risk of being sued or losing a suit. But the best protection against being sued is a good patient–doctor relationship [16]. Hiding, dissembling, or being indifferent about an event destroys trust and galvanizes a lawsuit much more than a sincere apology.

For example, some recommend apologizing for the effect on the child but not taking responsibility for the actual event. This apology is appropriate for a rash caused by an appropriately administered antibiotic. But it seems bizarre not to take responsibility when a clinician errantly administers a neuromuscular blocking agent instead of an anti-cholinesterase agent when attempting to antagonize muscle relaxation. Although an investigation should be done to assess for system flaws that contributed to the error, not taking responsibility in that case (unless there was a good reason) would likely aggravate parents.

Parents are naturally sensitive about the perioperative experiences of their children. Clinicians should consider apologizing or at least sympathizing about unpleasant experiences such as multiple, painful attempts to insert an intravenous catheter or an out-of-control inhalation induction of anesthesia. These discussions can include an acknowledgment that it was a bad experience and recommendations for the future. For example, a clinician could say, “I am sorry the intravenous catheter took so many sticks,” and “Next time, we should probably give oral sedation prior to attempting the intravenous catheter.” These comments simply acknowledge what happened, express regret, and educate the family for the future.

“Communication-and-resolution,” a transparent disclosure of injury or error presented with appropriate compensation, can lead to improved relationships with patients and families, better analysis of events to implement improvements, and possibly forestall legal action [91,92]. Defense of appraised care is essential for clinicians to participate in this system [93,94].

Production pressure

Production pressure is the ubiquitous “internal or external pressure on the anesthetist to keep the operating room schedule moving along speedily” [95]. As a consequence, clinicians may feel pressure to curtail preoperative discussions, inadvisably proceed with cases, or prematurely extubate the trachea to speed turnover. Clinicians should be aware of pressures to provide anesthesia inconsistent with their level of skill or to permit surgery in inappropriate settings. For example, the “routine” tonsillectomy for a child with achondroplasia may be too complex for some clinicians or some surgery centers. Clinicians have an obligation to their patients and to themselves only to provide care for which they are competent and to recognize when economic and administrative pressures induce them to do otherwise.

Suspicion of child maltreatment

Physicians are legally obligated to report even the suspicion of child maltreatment and may be criminally liable for not reporting it. It is natural to downplay concerns because of a hesitancy to inform authorities, particularly if the parents are from a socioeconomic class similar to the physician's. But child abuse should never be minimized as a one-time event. Early intervention minimizes disastrous consequences.

Children may be physically abused, sexually abused, emotionally abused, and neglected [96]. Clinicians may be the first to recognize child abuse because evidence of abuse frequently

occurs on the arms, hands, head, face, neck, and mouth. Signs of abuse include bruises or burns in shapes of objects, injuries that fit a biomechanical model (e.g. a handprint), fractures in infants, and developmentally inappropriate injuries that are not explained by the offered history. Child abuse might occur in the hospital during diagnostic or therapeutic care. Children with chronic cognitive delays or physical limitations are more prone to abuse [97]. Munchausen by proxy syndrome is a type of abuse in which parents either cause or fictionalize clinical problems in their children. The signs and symptoms of the resultant diseases are often difficult to explain coherently.

KEY POINTS: PROFESSIONALISM IN PEDIATRIC ANESTHESIA

- Pediatric clinicians have a societal responsibility to improve children's health through supporting professional or lay efforts in local, national, or international communities
- Disclose and apologize for medical errors promptly, factually, blamelessly, and with colleagues trained in disclosure and apology. Remember that clinicians are the “second victims” and deserve grace. Put in place systems to identify and support “second victims”
- Reject production pressure by treating each child as if they were your own

CASE STUDY

This case study is designed: (1) to emphasize that superficially defining cases such as “a 17-year-old wants to refuse transfusion therapy” overlooks relevant complexities; (2) to examine the process and relevant factors in determining maturity for medical decision making in an adolescent; (3) to provide an example of how dilemmas may be evaluated; and (4) to provide an example of the content in an ethics consultation. Characteristics of consultations include clarifying medical issues, identifying stakeholders and their relative extent of influence, defining the ethical questions and issues, and providing an assessment and recommendation.

Summary

Candace is a 17-year-old who has a rare type of rhabdomyosarcoma. She presents for resection of a tumor intertwined with major blood vessels. Candace is a Jehovah's Witness and wants to refuse receiving transfusion therapy during and after the resection of the tumor.

Medical questions

This type of rhabdomyosarcoma is too rare to reliably predict outcome. The best guess, though, is a 5-year survival of 5–10%. While there is a low likelihood of significant bleeding during the operation, the position of major blood vessels presents the possibility of sudden, rapid, and substantial bleeding.

Family

Candace is the daughter of Linda and Larry. Through a friend, Larry began exploring the Jehovah's Witness community 9 years ago and became baptized as a Jehovah's Witness 6 years ago. Linda describes herself as spiritual but has no interest in organized religion. She very much supports the authority of Candace's decision making.

Candace “was very skeptical the first month of learning about [the Jehovah's Witness religion]. I had friends who had ‘found’ religion ... but it never made sense to me.” Jehovah's Witness “made sense to me, in an easy to understand manner. This is it, this is the right religion.” Following thorough study, at age 14 she chose to become a baptized member to show her dedication to being a Jehovah's Witness.

Candace leads an active high school life. She is a starting wing on the field hockey team, and she frequently participates in school theater productions. She leads bible study and weekly youth group meetings. She is an accomplished public speaker, speaking to groups “over 100 people” about being a Jehovah's Witness.

Linda and Larry like the person Candace has become. Candace, Linda, and Larry share decision making about family matters. They have the normal disputes about things like curfew.

Candace is an active participant in her care. She asks appropriate and extensive questions about options and short- and long-term implications.

In private discussions with Candace, she emphasized that she did not want to die. However, because she believes that Bible and God forbid taking blood, receiving blood would fill her with incredible guilt and sadness because she had disappointed her God. While she was concerned that taking blood would separate her from God, her primary concern was the overwhelming sense of failing her God. When asked whether being transfused forcibly or while unconscious would ease her conscience, she answered that she would feel the same because she had actively put herself in a position in which she could involuntarily receive blood. She equated being transfused forcibly while unconscious as “rape.” She stated in a factual and calm way that “if I woke up and found I was getting blood, I would rip it out of my arm.”

Candace coherently articulates her religious and spiritual faith. Her beliefs are consistent with the teachings of her chosen faith community. She views herself as able to reason and be responsible for acting on personal moral judgments. She can imagine separating from the Jehovah’s Witness community if guided so by her conscience.

Ethical questions

1. If individuals of majority age have the right to refuse potentially life-sustaining transfusion therapy, do minors have this right?
2. What characteristics and criteria can be used to determine whether a minor possesses sufficient decision-making capacity and maturity to make this decision?
3. What issues should be discussed to ensure that their desired blood therapy wishes are followed?

Maturing adolescents are granted increasing authority in decision making. Relevant characteristics that give evidence of adolescent maturity and decision-making capacity include an understanding of their options and associated consequences, an internally coherent rationale, an ability to articulate their positions, an intellectual and emotional freedom to entertain alternate perspectives, and an indication of mature relationships with older individuals. Not all characteristics need to be present for an adolescent to be considered mature. The threshold for the evidence necessary to have decision-making capacity for a specific decision increases as the consequences of the decision increase.

Legitimate concerns about adolescents being overly influenced by short-term consequences should not be tainted by less relevant concerns that preferences may change as adolescents become older. Mature individuals are able to change their minds based on experience and evidence. That adolescents may change their mind as they mature does not invalidate current choices inasmuch as sufficient decision-making capacity is present.

Pragmatism affects considerations about whether to force adolescents to receive undesired healthcare. Adolescents are most capable of physical protest, either by yanking

intravenous catheters or by not presenting for therapy. For example, Billy Best, a 16-year-old with Hodgkin lymphoma, ran away so that he would not have to complete his chemotherapy regimen [98].

Assessment

The ethics advisory committee believes that Candace meets the requirements of being a mature individual with substantial decision-making capacity who understands the gravity of her choice. Her active participation outside the Jehovah’s Witness community indicates a wider view of the world rather than a more narrow view that may be present with exposure only to the Jehovah’s Witness community. Given her beliefs and her extensive missionary and teaching activities, we believe that she has thoughtfully chosen to become a Jehovah’s Witness. She has a loving and comprehensive relationship with her parents. Although her refusal of potentially life-sustaining therapy may lead to significant morbidity or death, we believe she exceeds the criteria to make these decisions.

Recommendations

1. The ethics committee believes that Candace should be considered primary decision maker.
2. We are aware that the surgeon requests a court order permitting Candace to be able to consent for refusal of potentially life-sustaining transfusion therapy. We encourage Candace and her family to seek as much information about this process as possible, including the process of seeking this status, the possible drawback of pursuing and securing mature minor status, the role of the parents after achieving this status, and the use of healthcare proxies. A court order may minimize chances that wayward individuals may transfuse Candace.
3. To ensure fidelity in regard to the hospital’s implicit promise to honor her preferences, a cadre of clinicians committed to honoring Candace’s wishes must be identified. Necessary clinicians include operating room nurses and technicians, anesthesiologists, trainee anesthesiologists, certified registered nurse anesthetists, surgeons, and post-operative nurses and physicians, particularly ICU physicians. Arrangements must be made to ensure willing clinicians in case of an emergent re-operation. The needs of these clinicians (e.g. to meet Candace) should be met.
4. This consultation is solely advisory. Our comments are restricted to the ethical interpretation of the issues facing Candace, her family, and the care team. You may wish to contact the Office of Legal Counsel for their input on existing regulations as well.

Postscript: A court order granted Candace the authority to make decisions about transfusion therapy. In informal conversation later, the judge declared that one of the primary considerations aside from Candace’s maturity was the very low likelihood of survival. If her possible survival had been higher, they would have been much less likely to grant Candace the legal authority to make decisions about transfusion therapy.

Annotated references

A full reference list can be found in the Wiley Companion Digital Edition of this title (see inside front cover for login instructions).

- 1 Greene NM. Familiarity as a basis for the practice of anesthesiology. *Anesthesiology* 1976; 44: 101–3. A precis of patient-care obligations of anesthesiologists. Greene disdains “do-what-you-are-familiar-with” anesthesia and declares that the complete anesthesiologist “orchestrates and selects anesthetic drugs and procedures to assure that each of his ... patients receives the best that modern anesthesia has to offer.”
- 3 Quill TE, Arnold RM, Platt F. “I wish things were different”: Expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med* 2001; 135: 551. The empathetic “wish” statement focuses on the patient and family and puts us on the same team. This article beautifully describes the power of these five words.
- 7 AAP Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics* 2016; 57: 414–16. This article is the fundamental explanation of informed consent for children.
- 13 Grootens-Wiegers P, Hein IM, van den Broek JM, de Vries MC. Medical decision-making in children and adolescents: developmental and neuroscientific aspects. *BMC Pediatr* 2017; 17: 1–10. This densely written article provides a comprehensive analysis of the neuroscientific aspects of adolescent decision-making capacities.
- 27 Menikoff J, Kaneshiro J, Pritchard I. The Common Rule, updated. *N Engl J Med* 2017; 376: 613–5. A succinct explanation of the 2018 updates to the ubiquitous Common Rule.
- 33 Weise KL, Okun AL, Carter BS, Christian CW. Guidance on forgoing life-sustaining medical treatment. *Pediatrics* 2017; 140: e20171905. This article is a clear explanation of what constitutes end-of-life benefits and burdens in children.
- 50 Kon AA, Shepard EK, Sederstrom NO, et al. Defining futile and potentially inappropriate interventions: A Policy Statement from the Society of Critical Care Medicine Ethics Committee. *Crit Care Med* 2016; 44: 1769–74. This definitive article clarifies the concepts of potentially inappropriate interventions and describes useful guidance for management.
- 79 Waisel DB. Nonpatient care obligations of anesthesiologists. *Anesthesiology* 1999; 91: 1152–8. This article describes the obligations of anesthesiologists to the speciality of anesthesiology and to society. The origin of the obligations, how to fulfill them, and the consequences of not fulfilling them are reviewed.
- 80 Gruen RL, Pearson SD, Brennan TA. Physician-citizens – public roles and professional obligations. *JAMA* 2004; 291: 94–8. This article provides a thoughtful perspective on obligations of physicians.
- 83 Lang K, Dupree C, Kon A, Dudinski D. Calling out implicit racial bias as a harm in pediatric care. *Cambridge Q Healthc Ethics* 2016; 25: 540–52. A friendly, direct analysis of healthcare disparities.