CHAPTER 1
Ethical Considerations

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Introduction

Although physicians may think of medical ethics in dramatic terms – withdrawing life-sustaining therapy, allocating organs for transplant – medical ethics floods our daily practice. Consider an anesthesiologist who recommends postponing surgery in an infant because of a borderline upper respiratory infection (URI) [1]. How should the anesthesiologist respond to a parental request to proceed? These decisions are often framed as medical decisions based on the characteristics of the URI and the surgery. But within the 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 (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 spends 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 a physician is faced with “oughts” – that which a physician is bound by duty to do – that conflict. In the above example, anesthesiologists ought to base proceeding with surgery solely on the child’s best interest. Anesthesiologists also ought to ensure that a child receives necessary healthcare within the realistic complexities of family life. Medical ethics provides the process by which to resolve these apparently conflicting “oughts.”

Resolving ethical dilemmas is not solely 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 enable ethics consultants to identify critical facts, apply ethical principles and case-based analysis, articulate precise questions, and have the moral imagination to create more palatable solutions.

Ethics committees and their consultation services provide the resources to help resolve dilemmas. Anesthesiologists may find consultation services particularly helpful with concerns about disagreements among
patients and clinicians, appropriate decision-making roles for adolescents, and decisions about end-of-life care. A typical free-standing children’s hospital has between six and ten ethics consultations each year, but some perform as many as 50 consultations annually [2].

Members of ethics committees include representatives throughout the hospital such as chaplains, administrators, social workers, nurses, and physicians. Many committees also include a local community representative. Depending on local practice, consultations may be performed by an individual, a small group or the entire ethics committee. Most ethics consultation services permit patients, parents and anyone with standing to request a consultation. Standing is defined broadly as participating in the care of the patient. 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 [3]. A committee with a strong record, however, does have substantial informal authority. The case study at the end of the chapter provides an example of an ethics consultation.

The law is not a desirable substitute for resolving ethical dilemmas. Most importantly, the law represents a lower boundary 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 relations. Crude statutes and regulations are unable to govern complex medical care. Consider the Baby Doe regulations regarding withdrawing therapy for neonates. The rigid regulations devastated the ability to apply thoughtful, tailored therapy to individual neonates [4–6].

Ethics committees also provide formal education sessions, ward ethics rounds, and institutional consultation. An example of an institutional consultation would be to determine and implement the necessary infrastructure to ensure compliance with an adolescent’s refusal to receive transfusion therapy.

**Informed consent process for pediatric patients**

The doctrine of informed consent centers on the belief that patients have a right to self-determination [7]. 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 health-care. But minors do have varying degrees of decision-making capacity, and should be included in medical decision making to the extent permitted by the child and situation (Box 1.1).

<table>
<thead>
<tr>
<th>Consent</th>
</tr>
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<tbody>
<tr>
<td>1. Adequate provision of information including the nature of the ailment or condition, the nature of the proposed diagnostic steps or treatment and the probability of their success; the existence and nature of the risks involved; and the existence, potential benefits, and risks of recommended alternative treatments (including the choice of no treatment).</td>
</tr>
<tr>
<td>2. Assessment of the patient’s understanding of the above information.</td>
</tr>
<tr>
<td>3. Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decisions.</td>
</tr>
<tr>
<td>4. Assurance, insofar as it is possible, that the patient has the freedom to choose among the medical alternatives without coercion or manipulation.</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Assent</th>
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<tr>
<td>1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.</td>
</tr>
<tr>
<td>2. Telling the patient what he or she can expect with tests and treatment.</td>
</tr>
<tr>
<td>3. Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).</td>
</tr>
<tr>
<td>4. Soliciting an expression of the patient’s willingness to accept the proposed care.</td>
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</table>

The process of pediatric informed consent depends on the age of the child (Table 1.1). The concepts 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 maker” 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 the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived” [7].

**Informed permission and the best interest standard**

To recognize the fact that ethical informed consent only can be given by the patient, the American Academy of
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...clinicians to assess the acceptability of the decision and, if necessary and appropriate, to participate in the discussion [8]. Anesthesiologists should seek to resolve disagreements without resorting to legal intervention. However, the state has an interest in protecting those who cannot protect themselves. If other options have failed, anesthesiologists should report parents they believe to be choosing unacceptable treatments to child welfare authorities for possible legal action.

**Informed assent: the role of the patient**

Children should participate in decision making to the extent their development permits [7]. For children between the ages of 7 and 13, anesthesiologists 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 a 12 year old wants an epidural for postoperative analgesia.

Anesthesiologists should assume that adolescents older than 13 years have sufficient decision-making capacity to fulfill the ethical obligations of informed consent. Adolescents have likely developed adult levels of abstract thought, complex reasoning and abilities to foresee and anticipate outcomes. However, adolescent decision-making abilities are limited by emotional impulsiveness and a tendency to undervalue long-term consequences. For these reasons, the influence an adolescent has on decision making is tempered by their 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. This is particularly important when predicting future outcomes for infants.

**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 [9].

**Disclosure**

The reasonable person standard, the legal standard for most of the United States, requires that the information disclosed satisfies the hypothetical reasonable person. For the most part, however, information to be disclosed to decision makers is not itemized. Further, preferences vary for the extent of disclosure and the desire to participate in decision making [10,11]. For example, in one typical survey, 74% of parents wanted to know all possible risks of anesthesia, while 24% wanted to know only those likely to occur, and 2% wanted to know only those that may result in a significant injury [12]. Rather than rely on a rote informed consent process, anesthesiologists should seek to satisfy the needs of the decision makers by meeting their information and decision-making needs. Because sociodemographic characteristics do not reliably predict preferences for disclosure and decision making, anesthesiologists should seek to meet the needs of the decision makers through patient-driven interactions. Anesthesiologists can do this by informing decision makers about that which the anesthesiologist feels must be communicated and about options that affect the perioperative experience (e.g., regional versus general anesthesia). The anesthesiologist can then ask if the decision makers wish to know more. Patient-driven interactions likely reduce malpractice lawsuits. The likelihood of being sued based on informed consent malpractice issues is very rare [13]. 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 [14,15].

**Informed refusal**

Informed refusal of a recommendation requires anesthesiologists 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. Anesthesiologists who believe parents are refusing necessary care for a child without decision-making capacity should use the best interest standard.

Children with significant decision-making capacity (perhaps around the age of 10 years but certainly by the age of 13 years) might refuse non-emergency procedures. Anesthesiologists 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 co-operation 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 clinicians, patient, and parents. Anesthesiologists 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.

Anesthesiologists should recognize the distinction between using pharmacological agents to calm an anxious adolescent to enable proceeding and using pharmacological 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 for the purpose of getting the patient to co-operate. On the other hand, it is wholly appropriate to seek the patient’s assent to receive sufficient anxiolysis so that upon return to the preoperative area, the patient is able to undergo the procedure. Time, respect, and simple strategies often resolve issues satisfactorily and efficiently.

**Confidentiality for adolescents**

Physicians are obligated to protect patient information from unauthorized and unnecessary disclosure. With adolescents, confidentially is crucial for even the banal. Adolescents concerned about confidentiality withhold pertinent information and defer necessary treatment [16]. Anesthesiologists may want to ask sensitive questions without the parents present. Squarely addressing confidentiality concerns often improves truthfulness.

Anesthesiologists in possession of sensitive information should encourage the adolescent to share the relevant information with the parents. It is useful to engage adolescent specialists or social workers to enable the adolescent to communicate successfully with the parents and to ensure future care. However, anesthesiologists should honor the adolescent’s right to confidentiality. It is ethically justifiable to breach confidentiality only when com-
plying with reporting statutes or when breaching confidentiality will prevent serious harm to the child or another. Anesthesiologists should confer with legal counsel to determine if a presumed legal obligation requires breaching confidentiality.

State statutes may limit the anesthesiologist to informing only the adolescent about a positive pregnancy test [17]. In addition to ethical principles and practical reasons, these statutes are specifically present to address concerns about child abuse in pregnant adolescents.

The ethical complexity increases logarithmically when a pregnant adolescent does not want to inform her parents and it is appropriate to postpone the procedure. Even though anesthesiologists must postpone the case in a manner that does not breach confidentiality, the details of how the postponement is communicated affects the ability to maintain confidentiality. For example, anesthesiologists 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, anesthesiologists may choose to deceive more actively. These clinicians would argue that if parents have no right to that information, then their obligations to the adolescent demand their best effort to maintain confidentiality.

Although peculiar in a medical textbook, perhaps a short course in deception is useful. Anesthesiologists 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 something 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 rules surrounding parental involvement in elective abortions are confusing [18]. Although many states require either parental consent or notification prior to an elective abortion, the exceptions to parental involvement make it prudent to consult with hospital counsel. In general, though, parental consent requires permission from parents while parental notification only requires informing parents. There are times when parental involvement in abortion may harm adolescents [18,19]. 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 if she is sufficiently mature to consent for an abortion. Even if the judge determines that the adolescent is insufficiently mature, the judge may grant permission for the abortion if the judge believes it is in the adolescent’s best interest.

**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 [20]. Anesthesiologists 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. Anesthesiologists should use the best interest standard to guide therapy acutely. Consider a 15 year old with an acute cervical fracture who refuses emergency stabilization, which may cause irreversible 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 emergency therapy in this case.

**Children of Jehovah’s Witnesses**

Jehovah’s Witnesses interpret biblical scripture to mean that anyone who takes blood will be “cut off from his people” and not receive eternal salvation [21,22]. Adults may refuse potentially life-sustaining transfusion therapy. The presumption is that they are making an informed and voluntary decision. But the courts routinely authorize transfusion of children of Jehovah’s Witnesses. The courts base these decisions on the doctrine of *pares patriae*, the obligation of the state to protect the interests of incompetent patients.

Anesthesiologists should directly address transfusion therapy when caring for a child of Jehovah’s Witnesses. The patient 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 anesthesiologist 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 critical
situations, the anesthesiologist will transfuse while concomitantly seeking legal authorization. Anesthesiologists should be familiar with the hospital’s preferred mechanism for obtaining legal authorizing. 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, anesthesiologists may choose to obtain the court order preoperatively if there is a 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.

Consent for pediatric procedures without direct benefits

Pediatric anesthesiologists may encounter children undergoing bone marrow donation for siblings who would benefit from hematopoietic stem cell transplantation [23]. 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 and pediatric donors report that the benefits of donations outweigh the physical harm [24]. 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, a likelihood of benefit to the recipient and an absence of a suitable medically equivalent adult relative.

The temporarily impaired parent

Chemically intoxicated parents may be disruptive, dangerous, and incapable of fulfilling surrogate responsibilities. Anesthesiologists 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 [25].

Although it seems ethically and legally prudent to postpone routine treatment until informed permission and legal consent can be obtained from an unimpaired parent, anesthesiologists will have to 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. Anesthesiologists should consult with legal and risk management colleagues for guidance.

Molecular genetic testing

The combination of genetic testing and electronic medical records permits anesthesiologists to be aware of testing used to confirm a diagnosis, determine carrier status or for asymptomatic testing for disorders of late onset [26]. While genetic testing provides substantial benefits, it can also do harm by informing people about their genetic lineage without the patient’s consent or adequate preparation.

Whether to test is particularly hazardous with minors. Genetic testing may affect personal psychosocial development and business 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 [26].

Forgoing potentially life-sustaining therapy

Do-not-resuscitate orders

Do-not-resuscitate orders enable patients to forgo potentially life-sustaining treatment (LST) because the likely burdens outweigh the potential benefits. Benefits of receiving LST may include prolongation of life (understanding that the continuation of biological existence without consciousness may not be a benefit); improved quality of life after the life-sustaining medical therapy has been applied (including reduction of pain or disability); and increased “physical pleasure, emotional enjoyment, and intellectual satisfaction” [27]. Burdens should be viewed from the patient’s perspective and may include “intractable pain; irremediable disability or helplessness; emotional suffering; invasive and/or inhumane interventions designed to sustain life; or other activities that severely detract from the patient’s quality of life” [27]. Benefits and burdens should be considered in terms of both short- and long-term goals.

Children with do-not-resuscitate orders seek benefits from procedures that decrease pain, provide vascular
access, enable living at home or treat an urgent problem unrelated to the primary problem (e.g. fractures). Potential burdens from procedures may be due to either the resuscitation attempt or to function or cognitive decrements that may follow resuscitation.

The American Society of Anesthesiologists, the American Academy of Pediatrics and the American College of Surgeons recommend mandatory re-evaluation of the do-not-resuscitate order before going to the operating room [28–30].

Re-evaluating the order prior to surgery requires clarifying the goals for the procedure and end-of-life care through discussion with the patient, parents, and relevant clinicians such as surgeons and primary care physicians. Children should be involved in a developmentally appropriate manner. In practice, the re-evaluation of the do-not-resuscitate order for the perioperative period should result in either full resuscitation or a goal-directed approach toward perioperative resuscitation.

Discussions with the relevant decision makers should emphasize the differences between the operating room and the ward. Perioperative care permits a more personalized, real-time determination of whether resuscitation efforts would be consistent with the end-of-life goals. In the operating room, specific clinicians care for the patient for a defined period of time. Detailed knowledge of the goals for end-of-life care permits anesthesiologists and surgeons to tailor the extent of resuscitation to the likelihood of achieving those goals. In the dynamic surgical environment, the ability to respond flexibly, based on goals, is necessary to allow clinicians to thoughtfully enact limits on resuscitation. Additional information to give decision makers is listed in Box 1.2 [30].

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**Box 1.2 Components of the discussion to re-evaluate do-not-resuscitate orders for the perioperative period [29,30,32]**

- Planned procedure and anticipated benefit to child
- 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
- Discussion of the response to iatrogenic events
- Intended and possible venues and types of postoperative care
- Postoperative timing and mechanisms for resuscitation and for re-evaluation of limitations on resuscitation
- Establishment of an agreement through a goal-directed approach or revocation of the DNR order for the perioperative period
- Documentation

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Do-not-resuscitate directives that list acceptable interventions (e.g. tracheal intubation, chest compressions, etc.) are impractical in the operating room. Reaching an agreement can be difficult because of unclear distinctions between anesthetic practice and resuscitation [31]. Inflexible directives increase the chance that physicians will get “caught” in a technicality that is inconsistent with the patient’s desires. For example, a restriction on tracheal intubation that is intended to limit a lengthy intensive care unit stay is not intended to refuse a presumably short-term tracheal intubation resulting from opioid-induced apnea during monitored anesthesia care. This “do what I mean, not what I say” dissonance leads to physicians using their reasonable beliefs to violate directives. But using a system that requires physicians to violate patient directives to fulfill patient wishes will eventually result in unnecessary and harmful violations. In addition, it inexorably weakens the perceived importance of following policies and directives.

Goal-directed approaches permit patients to guide therapy by prioritizing outcomes (e.g. “I don’t want to suffer in the ICU for 2 weeks before I die”). After decision makers define goals, operating room physicians can 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 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 [29,32]. For these reasons, decision makers may choose to modify their previous limits on resuscitation for the perioperative period.

From clinical experience, the vast majority of decision makers that choose to use a goal-directed approach authorize temporary therapeutic interventions to manage quickly and easily reversible events, but reject those interventions that will likely result in permanent sequelae, such as neurological impairment or dependence upon life-sustaining technology [29]. 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 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 the appropriate extent of postoperative therapy. Patients may want a trial of therapy before concluding that the burden of continuing therapy outweighs the 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.

**Barriers to honoring perioperative limitations on life-sustaining therapy**

Barriers to honoring perioperative limitations on LST center on insufficient knowledge about policies, law, and ethics. Many anesthesiologists and surgeons still believe that do-not-resuscitate orders must be revoked when patients come to the operating room.

Others worry, wrongly, that honoring limitations on LST may result in being sued. Statutes that address requirements for do-not-resuscitate orders often include immunity provisions that protect physicians from liability [33]. Indeed, the risk of liability for honoring an appropriately documented do-not-resuscitate order is likely to be lower than the risk of not honoring it [33].

Perhaps a more subtle barrier to honoring these directives is the response of clinicians to iatrogenic events [34]. Some anesthesiologists will initiate resuscitation solely because the etiology was iatrogenic rather than the patient’s disease [35-37]. But by instituting perioperative limitations on LST, decision makers have declared that their sole concern is the physical and mental status following the arrest [38]. Anesthesiologists should initiate and continue resuscitation based solely on achieving the patient’s goals.

Attitudes affect end-of-life care [39-41]. Clinicians are more likely to honor a refusal of resuscitation for a palliative procedure than for an elective procedure [30]. Clinicians prioritize imminence of death when considering the appropriateness of a patient’s desire to limit LST while patients, on the other hand, prioritize functional status when choosing to refuse LST [34]. This dissonance affects the ability of clinicians to implement perioperative LST.

**Concepts of inadvisable care and futility**

Most of the confusion surrounding the concept of futility comes from imprecise terminology [42]. Futile therapy should be considered as treatments that cannot accomplish a specific, intended goal. In that sense, dilemmas about whether to use futile therapy rarely arise. Treatments with low likelihood of success, on the other hand, may be considered inadvisable because of the benefits and burdens of proceeding, but they cannot be considered futile. A treatment may be considered inadvisable because of burdens to the child, cost or uncertain benefit.

At the clinician level, discussions about inadvisable care center on the benefits and burdens to the child. Qualitative and quantitative considerations should be defined carefully and physicians 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 near the end of life should be based on the best interests of the child and not on cost.

Hospitals should have established processes for resolving conflicts. However, the ethical underpinnings of conflict resolution prioritize parental preferences as determined by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (Table 1.2) [4]. Clinician preferences only supersede parental preferences if a therapy is clearly beneficial.

<table>
<thead>
<tr>
<th>Physicians consider treatment clearly beneficial</th>
<th>Parents prefer to accept treatment</th>
<th>Parents prefer to forgo treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treat</td>
<td>Provide treatment during review process</td>
<td></td>
</tr>
<tr>
<td>Treat</td>
<td>Forgo</td>
<td></td>
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<tr>
<td>Review</td>
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Table 1.2: Suggested grid for resolving disputes about appropriate care (modified) [4]
Withdrawing mechanical ventilation therapy

The extent and type of sedation given when mechanical ventilation therapy is being withdrawn should be based on benefits and burdens. The benefits of administering sedation to minimize discomfort and suffering usually outweigh the burdens of an ever-diminishing likelihood of survival. Providing skillful withdrawal therapy is difficult and anesthesiologists should not assume that without training or experience they can provide high-quality end-of-life care [43–45]. Anesthesiologists should not use paralytic agents to hide patient movements during withdrawal of therapy [46]. Even though patient movements may upset parents, use of paralytic agents will hide the signs of distress that physicians use to titrate analgesia and sedations. Explaining this to family members may help them tolerate otherwise upsetting movements or event.

Other topics in pediatric anesthesiology

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 [47]. 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.

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 [48,49]. Assent may be waived if there is the prospect of direct benefit to the child that is available only through participation of 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 1.3). The hallmark of these categories is that potential benefits must increase commensurate with potential risks. Most controversy about pediatric research relates to 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” [50,51]. The common interpretation is that minimal risk refers to risks encountered by healthy children, such as playing sports and riding in a car [53,54]. Some use a more relative interpretation, basing the standard of “daily life” on the events to which children enrolled in the research are 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 a “minor increase over minimal risk” [50]. “Minor increase over minimal risk” has been interpreted as pain, discomfort or stress that is transient, reversible and not severe [53]. 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 [55].

“Condition” is used to mean characteristics “that an established body of scientific or clinical evidence has shown to negatively affect children’s health and well-being or to increase the risk of developing a health problem in the future” [53,55]. For example, consider a protocol to assess insulin resistance in obese children who do not have type II 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 [55].

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 process may minimize the inaccurate estimations of risk that hinders appropriate research and permits 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 [54]. 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 [58].

**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 [59,60]. “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.

Pediatric anesthesiologists have actively taken up this obligation (Fig. 1.1). One of the more notable activities has been the development of specialty organizations, like the Society for Pediatric Anesthesia and the American Academy of Pediatrics Section on Anesthesiology and Pain Medicine. Organizing engages the wisdom and energy of like-minded individuals to identify concerns, define goals and implement solutions. For example, the pediatric anesthesiology fellowship programs advocated becoming an ACGME-accredited fellowship to ensure a standard for training programs for pediatric anesthesiologists [61].

Collaborative projects gather data about rare events to help determine ways to prevent them. The Pediatric Perioperative Cardiac Arrest Registry began in 1994 and has provided useful information in understanding the causes of pediatric cardiac arrest. Wake Up Safe is a similar registry designed to assess serious adverse events and recommend how they can be prevented. It is every anesthesiologist’s obligation to participate in efforts like these.
Physicians should fulfill obligations to society by participating in activities that are consistent with the individual’s “expertise, interests and situations” [60]. For pediatric anesthesiologists, one appropriate approach would be to participate in the initiatives of relevant professional organizations. Anesthesiologists should consider addressing relevant public health issues such as pediatric obesity, pediatric tobacco use and second-hand smoke, and socio-economic disparities in healthcare and healthcare access [60,62–64].

**Safety and quality care initiatives**

Anesthesiologists have an obligation to foster patient safety. This obligation requires participation in surveillance data collection and compliance with policies intended to improve care, such as perioperative time-outs to ensure the right patient is receiving the right procedure [65,66]. Implementation of seemingly unnecessary policies often meets with resistance but it is difficult for individual physicians to appreciate the broad perspective from their individual perches. Anesthesiologists need to accept the limitations of their vantage point and willingly incorporate safety activities to further the common good. But they also should voice concerns through appropriate channels about poor or inadequate policies. Resorting to workarounds prevents policy remediation and encourages selective following of policies, which in turn causes more medical errors.

**Apology and disclosure**

Parents wish to be informed about medical errors that harm or may harm their children [67,68]. They also wish to receive appropriate apologies. Yet clinicians discount these clear desires. Barely half of pediatricians would disclose a serious error and fewer than a quarter would apologize for the same error [69]. Principles of respect of autonomy and truth-telling require physicians to be forthright about medical errors.

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 [70]. But lore and literature indicate that the best protection against being sued is a good patient–doctor relationship [14]. Hiding, dissembling or being indifferent about an event will likely do more to galvanize a lawsuit and destroy trust than a sincere apology.

For example, some recommend apologizing for the effect on the patient but not to take 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 an anesthesiologist errantly injects a neuromuscular blocking agent instead of an anticholinesterase agent when attempting to antagonize muscle relaxation. Common sense suggests that not taking responsibility in that case (unless there was a good reason) would aggravate parents.

Thoughtful full disclosure should commence upon recognition of the problem [71,72]. Ethics aside, anesthesiologists should ignore the temptation to withhold disclosure. Parents will eventually learn what happened and will wonder, likely with animosity, why such information was withheld. Anesthesiologists should share what is known but 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 patient and family should be given a contact person who will be available to answer questions, arrange meetings, explain the results of the investigation and describe the plan to prevent comparable events.

Parents are naturally sensitive about the perioperative experiences of their children. Anesthesiologists 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, an anesthesiologist 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.

**Production pressure**

Production pressure is the ubiquitous “internal or external pressure on the anesthetist to keep the operating room schedule moving along speedily” [73]. As a consequence, anesthesiologists may feel pressure to curtail preoperative discussions, inadvisably proceed with cases or prematurely extubate the trachea to speed turnover. Anesthesiologists 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 achondroplastic dwarfism may be too complex for some anesthesiologists or some surgery centers. Anesthesiologists have an obligation to their patients and to themselves to only
provide care for which they are competent and to recognize when economic and administrative pressures induce them to do otherwise.

**Suspicion of child abuse**

Physicians are legally obligated to report even the suspicion of child abuse [74,75]. It is natural to downplay concerns because of a hesitancy to inform authorities, particularly if the parents are from a socio-economic class similar to the physician’s. But child abuse should never be minimized as a one-time event. Early intervention minimizes disastrous consequences.

Anesthesiologists may be the first to recognize child abuse because evidence of abuse frequently occurs on the arms, hands, head, face, neck, and mouth [76,77]. 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. Anesthesiologists should be aware that child abuse might occur in the hospital during diagnostic or therapeutic care [78,79]. Munchausen by proxy is a type of abuse in which parents either cause or fictionalize clinical problems in their children [80]. The signs and symptoms of the resultant diseases are often difficult to explain coherently.

CASE STUDY

This case study is designed to emphasize that superficially defining cases such as “a 17 year old wants to refuse transfusion therapy” overlooks relevant complexities; to examine the process and relevant factors in determining maturity for medical decision making in an adolescent; to provide an example of how dilemmas may be evaluated; and 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**

Seventeen-year-old Candace 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 transfusion therapy during and after the resection of the tumor.

**Medical questions**

This type of rhabdomyosarcoma is too rare to be able 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 so guided 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 be 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 alternative 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.

The case of Phillip Malcolm describes a child without decision-making capacity. Phillip and his parents were not permitted to refuse transfusion when the almost 18-year-old Phillip was acutely diagnosed with severe anemia and cancer [81]. Transfusions were recommended to stabilize his clinical status. The court learned that although the family had joined the religion 3 years earlier, Phillip did not become interested until 1 year ago. Phillip understood the “basic tenet of the religion’s prohibition regarding blood transfusions” but had rudimentary knowledge about the Bible. He did not consider it a sin if the court ordered a transfusion. Phillip had not shown independent or shared decision making in his relationship with his parents.

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 [9]. On the other hand, following an accident, 16-year-old Greg Novak was thought to urgently require transfusion therapy [82]. Being Jehovah’s Witnesses, Novak and his parents refused transfusion therapy. However, a court-appointed guardian requested transfusion therapy. Novak was physically restrained and transfused.

Assessment

The 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 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 Continued
Annotated references

A full reference list for this chapter is available at:
http://www.wiley.com/go/gregory/andropoulos/pediatricanesthesia

7. Committee on Bioethics, American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. Pediatrics 1995; 95: 314–17. This article is the fundamental explanation of informed consent for children. Pay particular attention to the introduction, in which Dr William Bartholome (in absentia) exhorts clinicians to respect “the experience, perspective and power of children.”


42. Consensus Statement of the Society of Critical Care Medicine’s Ethics Committee regarding futile and other possibly inadvisable treatments. Crit Care Med 1997; 25: 887–91. This article expalnates the importance of recognizing the ethical and clinical differences between futile treatment and other inadvisable treatments and expands on the classifications used in this chapter.

59. Waisel DB. Nonpatient care obligations of anesthesiologists. Anesthesiology 1999; 91: 1152–8. This article describes the obligations of anesthesiologists to the specialty of anesthesiology and to society. The origin of the obligations, how to fulfill them and the consequences of not fulfilling them are reviewed.


61. Rockoff MA, Hall SC. Subspecialty training in pediatric anesthesiology: what does it mean? Anesth Analg 1997; 85: 1185–90. This article explains the reasoning underlying the formalizing of specialty training in pediatric anesthesiology. The reasoning exemplifies the touchstone that should be at the forefront of policy decisions about pediatic medicine: to benefit children.

83. Greene NM. Familiarity as a basis for the practice of anesthesiology. Anesthesiology 1976; 44: 101–3. A précis of the 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 recives the best that modern anesthesia has to offer.”

84. Kon AA. Answering the question: “Doctor, if this were your child, what would you do?” Pediatrics 2006; 118: 393–7. This article helps anesthesiologists understand and answer this frequent and deceptively simple question.