Children Who Refuse Surgery: A Case-Based Discussion

Moderators:

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Objectives:

1. To understand the legal rights of minors refusing surgery
2. To understand the ethical rights of minors refusing surgery
3. To review the current laws in the United States regarding this matter
4. To discuss options for anesthesiologists faced with this issue

Case History:

12 y.o. female presents for septo-rhinoplasty. During the preoperative evaluation, her mother relays that she is very excited about the surgery for her daughter as “her nose is so crooked I’m worried other children will tease her...this is the best thing for her.” The child is sullen and has limited interactions.

Questions: What “red flags” does this information raise? Given only this information, how would you proceed? What questions would you ask? Would you ask the child what they are thinking? Would you continue with H and P and “ignore” the child’s attitude? Would you ask the parent to step out of the room while you talk with the child?

Case History Continued:

When it is time to go to the operating suite, the child refuses to cooperate stating that her mom wants the surgery, not her, and that she likes her appearance the way it is. She will not discuss the issue further and starts to protest loudly when any attempt is made to proceed.

Questions: What is your next step? Do you force the child to proceed? Do you call the surgeon? What role does the surgical team play? Is there a difference between the types of surgery? What if this case was an appendectomy for ruptured appendicitis? Do you know your institution’s policy on children and consent/assent? What is your legal obligation? Is it important to ascertain competency of the child? How would you do this in the preoperative setting?
Case History Continued:

The surgeon is called and he defers to “anesthesia” not wanting to get involved. The mother insists that her daughter is just anxious and would relax if given “something to take the edge off.” The child does not want any medications.

Questions: What about premedication? What about restraints?

Case History Continued:

Upon further discussion with the child, she states that she has always felt “pressured” by her mother to be “prettier.” She is a good student, making A’s and B’s in school, participates in sports and has many friends. She does not get teased about her appearance as her mother is worried about. She is concerned about undergoing anesthesia for the surgery, she saw a movie about someone being awake and not being able to talk while having surgery. She is also concerned about the level of pain she will have and having to miss a week of school while recovering.

Questions:

Are these valid concerns? How would you proceed? Would you cancel the case? Would you find another less concerned colleague to administer the anesthetic? Would you recommend rescheduling after a period of counseling? Medico-legally what are you obligated to do, not do? What is the definition of beneficence? Non-maleficence? Autonomy? Justice?

Discussion:

Adults with sound mind are given the privilege of refusing to continue at any stage of a procedure. If ignored, the continued care may be considered an assault on the patient. Children however, do not share the same rights. The official age of minority requiring parental consent in the United States is 18. According to a recent study, children refusing surgery and thereby anesthesia may be more common than previously thought. In 2007, Lewis et al surveyed 852 anesthesiologists in the USA regarding the issue of children refusing surgery. Forty-five percent of respondents (453) stated that they had cancelled one or more cases for child refusal during their career. The same study also found that as the age of the child increased, fewer respondents felt comfortable using restraints.

There are two main historical cases/Acts that must be mentioned in the discussion of the legal rights of minors. The Gillick case is a sentinel case in the literature regarding children’s right for
consent. It is based on young sexually active girls having the right to request and receive contraception without parental knowledge or consent. Lord Scarman, in the British House of Lords, was in favor of child competency and decision making stating “parental right yields to the child’s right to make his own decision when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision.” The Gillick ruling does not specify a particular age of decision making, but rather forms the idea of maturity and competency vs. age.

The Children Act of 1989 describes the welfare of a child as the guiding principle with which clinicians should base decisions. The first item in this welfare checklist is listed as “the ascertainable wishes and feelings of the child considered in the light of his age and understanding.” This act makes provision for the physician to make such a decision; however, the act does not distinguish between consent for treatment and refusal of treatment. The final legal authority for consent still lies with the guardians or parent who would, hopefully, make a sound decision based on advice from the physician holding the child’s best interest of highest importance.

The issue of consent/assent in medical procedures for children has been discussed repeatedly. A true informed consent in a pediatric case involves assent by the child and parental proxy consent. Assent is defined as the developmentally appropriate transfer of information regarding treatment and acceptance by the patient for that treatment. Thus, it is paramount to assess the competency of the child to self-determine their care. Most clinicians would not take pause at an under-aged child assenting to proceed with surgery, however if they refuse, then the clinician finds themselves in a quandary.

There is differing legal guidance in the United States regarding children’s rights as minors when concerned with refusal of surgery and anesthesia. There is often variation from state to state. The American Academy of Pediatrics has released guidelines concerning consent for treatment in minors. They maintain that legal exceptions to informed consent are medical emergencies; minors who are emancipated whether by marriage, court ruling, or military service; certain conditions such as pregnancy; and “mature minors.” This idea of a “mature minor” is a child 14 years of age or older who is “sufficiently mature and possesses the intelligence to understand and appreciate the risks, benefits and alternatives of the proposed treatment, and who is able to make a voluntary and rational choice.” If a child is deemed a “mature minor” and continues to refuse the treatment, then one must utilize the ethical concepts of beneficence, non-maleficence, autonomy, and justice to arrive at a solution.

There are several alternatives for anesthesiologists faced with this dilemma. It is advisable to try to fully understand the situation, parent’s opinion and child’s, prior to proceeding. If the parent’s position in unaltering and the child maintains refusal, then a postponement for
elective treatments is in order. A hospital ethics committee consultation prior to undertaking the procedure may also be of benefit. The anesthesiologist cannot be faulted for deferring elective treatments for further evaluation of competency, including psychiatric counseling for the child if so needed. If the anesthesiologist is able to ascertain that the child is not competent but still feels ill at ease with proceeding, they may offer a colleague’s participation instead of their own.

References: