

## **Title: An Adolescent's Refusal of Surgery**

**Author(s): Cynthia Tung, MD, David Waisel, MD, Charles Berde, MD, PhD**

**Affiliation(s): Children's Hospital Boston, Harvard Medical School, Boston, MA**

### **ABSTRACT BODY:**

**Introduction:** Decision-making authority regarding a child's health care generally belongs to the parent, who most agree will act in the best interest of the child. As a child becomes an adolescent, decision-making becomes more complex as we try to incorporate the adolescent in the process. We present a 16-year-old male, with several medical conditions, who initially assented to anesthesia and surgery and then, after entering the operating room, refused intervention.

**Case Report:** A 16-year-old male with Duchenne's muscular dystrophy, progressive scoliosis associated with hip and low back pain, severe restrictive lung disease, and cardiomyopathy, was scheduled for a posterior spinal fusion. Three years prior, the patient was anesthetized for planned repair of his scoliosis. At the time, he was noted to be a difficult airway and, ultimately, the case was cancelled because he was difficult to ventilate once he was prone. After that event, the patient and his mother made the decision to continue with his life without the scoliosis repair. However, because of progressive hip and low back pain which affected the quality of his life, the possibility of surgical correction was revisited. Given the severity of this patient's cardiomyopathy, restrictive lung disease and airway issues, lengthy discussions among the patient's surgeon, anesthesiologist, otolaryngologist, pulmonologist, cardiologist, and counselor took place. The patient and his mother were informed of the risks and benefits of proceeding; in particular, that risk of a life-threatening cardiac event or death was between 10-20%. On the other hand, they were informed that successful completion of the procedure and postoperative recovery could improve his quality of life, preserve respiratory function, and increase his longevity. Eventually, the patient and his mother decided to proceed with the surgery.

On the day of surgery, the patient was seen in the holding area, a peripheral intravenous catheter was placed, and he received midazolam 0.5 mg and scopolamine 0.16mg in preparation for a planned sedated fiberoptic intubation. Upon transfer to the operating room table, the patient became very anxious and repeatedly stated: "Stop. I don't want to have the surgery." He was conscious and very clear about his refusal to proceed. Monitors were placed to assure no hypoxemia and normal vital signs. The surgeon, and a hospital ethicist were contacted, and the patient's mother was brought into the OR. The patient was pharmacologically reversed with flumazenil and physostigmine. When he continued to appear to be at his baseline mental status and remained adamant against the surgery, the risks and benefits of proceeding were discussed again with him and his mother. The patient's mother then agreed to cancel the surgery and the patient was transferred to the PACU. He had an uneventful two-hour course in recovery and was discharged home.

Subsequently, the patient decided to have the surgery. After further lengthy preoperative counseling, the patient had successful repair of his scoliosis, is fully recovered and doing well at home five months later.

**Conclusion:** This case brings up the complexities of incorporating adolescents into decision-making and evaluating an adolescent's capacity to make decisions about his health care.

Empirical data exists that, when given various medical scenarios, 14-year-olds have similar abilities to reason and understand treatment alternatives as their adult counterparts. Adolescents are also capable of abstract and operational thought, compared to very young children who think in more concrete terms. Thus, we override a 5-year-old who says 'no' to an appendectomy because 1) the procedure is of an emergent nature, 2) serious harms can occur if the surgery is not performed, and 3) a child this age does not have the capacity to understand the risks to his health if left untreated. In contrast, we accept the refusal of treatment by this 16-year-old with progressive disease because 1) his scoliosis repair is of a non-emergent nature, 2) refusal of this surgery will not immediately impact or threaten his health, and 3) he understands that there is a risk of death associated with the surgery, but also knows too well that without the surgery he will continue to experience pain from his disease and decline in his lung function. Moreover, an adolescent with a chronic, progressive disease will require many future hospital visits. Including him in the decision making process not only builds his trust with physicians, but will also teach him how to be responsible for his health care as he develops into an adult. This case also brings forth increased recognition of the power of sedation and physical location on honoring patient wishes. A refusal that would be otherwise valid is equally valid both after sedation and in the operating room, particularly in the circumstances outlined above, and particularly when decision-making can be enhanced by pharmacologic reversal of sedation.

The American Academy of Pediatrics encourages physicians to obtain assent from the developmentally-appropriate pediatric patient and informed consent from the adolescent patient. We have a responsibility to recognize an adolescent's capacity to make decisions and provide the proper counseling and support so that we can honor those decisions at the appropriate times.

### **References**

Pediatrics 95(2): 314-17, Feb 1995.

Kennedy Institute of Ethics Journal 10(2): 147-63, 2000.

Anesthesiology 87(4): 968-78, Oct 1997.