Session 5. Minors as Decision-Makers

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Overview
Some empirical evidence suggests that on average, 14-year-olds have cognitive or reasoning capacity equivalent to 20- to 22-year-olds. However, information from social psychology studies indicate that as a group, teenagers have at least 3 characteristics that may limit the quality of decisions they make: 1) teens have a high tolerance for risk; 2) they attend primarily to short-term consequences of their actions; and 3) they are more easily influenced by others (eg, peers, parents) than they will be when somewhat older. In addition, neuropsychological studies have begun to show that brain capacity does not mature until approximately 25 years of age.

Our society, for complex social and political reasons, permits independent decision-making for most matters, including health care, at age 18 years. Despite accumulating science indicating caution about this arbitrary age cutoff, we generally uphold 18 as the age of majority. Further complexity enters into this because some minors, though by no means all, with chronic medical conditions and considerable experience in the health care system seem mature beyond their years. Arguably, such medically mature minors should have decision-making authority well before their 18th birthdays.

Instructor’s Guide

- Case Summary
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Case Summary
Jane was diagnosed with cystic fibrosis (CF) at age 9 months because of failure to thrive and a recurrent cough. Now 16 years old, her lung function has deteriorated to the point of consideration for lung transplantation. Jane has been in the intensive care unit (ICU) for mechanical ventilation 3 times. Two of those episodes of respiratory failure required more than 3 weeks each of mechanical ventilation, though the most recent lasted only 4 days. At a pulmonology clinic visit Jane tells her physician and parents that she does not want a transplant. She indicates that transplantation would likely require weeks to months in the hospital and much more time in the ICU on a ventilator, after thinking about it and talking with her pastor she feels she wants palliative care and no more trips to the ICU. Jane, well aware of her failing lungs, does not wish to undergo lung transplantation despite the potential of the procedure to add years to her life. She feels that the rigors of surgery and subsequent ICU care and medications would mean a poor quality of life no matter how much longer she would survive. Her parents and
physicians, surprised by her announcement, do not know how to best respond to what Jane has said.

- Are adolescents capable of making their own health care decisions, especially major ones like refusing transplantation?
- Under what circumstances would a minor be legally allowed to make autonomous health care decisions?
- How does a physician address conflict between the patient’s desired course of medical action and the parents’?

Alternate Cases
1. Tom, at 17 years of age, smokes marijuana 3 to 4 times a week. A talented painter, Tom defends the practice on the grounds that it enhances his artistic abilities. Hospitalized for injuries he incurred while driving stoned, Tom refuses to meet with a substance abuse professional.

2. Ginny, at 15 years of age, is about to graduate from high school and enter a state university program for gifted youth. A model daughter until now, she has entered a rebellious phase and despite knowing better, fails to prevent becoming pregnant. Ashamed, she tells her parents of her condition and requests their help obtaining pregnancy termination. Based on their strong religious convictions, Ginny’s parents insist she carry the baby to term and give it up for adoption.

3. Steve, a 16-year-old, has isolated growth hormone deficiency. He has received recombinant growth hormone (rGH) injections daily for the last 7 years and a recent bone age radiograph indicates he has approximately 15 months of additional potential linear growth with continued rGH. A serious musician—he plays first violin in a statewide youth orchestra—he feels no need to grow taller than the 5 feet 4 inches he has attained. He hates the daily injections and wants to stop.

4. Carole, a 14-year-old, develops a sore throat, fever, a headache, and abdominal pain. The result of a rapid group A beta-hemolytic streptococcus test in her pediatrician’s office is positive. Carole knows that she and her mother routinely fail to complete prescribed treatment regimens, and the teen requests an injection of penicillin rather than have to take pills for 10 days. Carole’s mother refuses on the grounds that insurance will pay for the oral penicillin but not the $50 for intramuscular penicillin.

5. Andy and Steve are identical 15-year-old twins. Andy has developed hemolytic uremic syndrome induced by Escherichia coli followed by acute, then chronic renal failure. Andy’s kidney specialist tells the family that Andy will need a kidney transplant. On his own, Steve researches the situation and discovers he is the ideal immunologic donor for his brother. He tells his family that Andy should not go on the cadaver kidney transplant list because he (Steve) will donate a kidney. Undergoing the operation will mean Steve has to give up his chance to become the state wrestling champion in his weight class, a goal Steve and his dad have had for years.
Examples From Case Law
1. Case of BA (1998): A 15-year-old male refused immunosuppressive medications after his second liver transplant because of severe side effects and poor quality of his life. The family supported the teen’s decision. Physicians filed charges of medical neglect. The judge ruled in favor of the patient, who died 1 month after immunosuppressive medications were stopped.
2. Case of EG (1987): A 17-year-old female and her family refused transfusions as part of necessary supportive care for newly diagnosed acute myeloblastic leukemia. The court initially rejected EG’s petition for mature minor status and authorized transfusions. This decision was reversed years later, and mature minor status was granted to EG to make decision to refuse transfusions. This decision did not help the patient in question but established a precedent for future cases.

Learning Objectives
1. Define the circumstances under which a minor would be legally allowed to make autonomous health care decisions.
2. Discuss how the adolescent and brain development literature influences the approach to minors as decision-makers.
3. Identify key questions to guide conflict resolution in settings in which an adolescent and the parents disagree with the best course of medical action.
4. Examine the rational for court intervention.

Suggested Reading for Instructor


Further Reading
Case Discussion

What factors should be considered in allowing a minor to refuse medical treatment (in this case, transplantation)?

1. Issues related to basic informed consent
   - How, if at all, would these differ for our patient from considerations for a 35-year-old making a similar decision?
   - Does the patient have the cognitive capacity to understand information presented to her, process it appropriately, and make an adequate decision?
   - Does the patient appear to weigh risks and benefits of the proposed treatment based on the medical information and personal (patient goals of care) factors?
   - Is this decision consistent with prior decisions the patient has made and with the patient’s values and priorities?

2. Why is the patient really refusing treatment?
   - Before we consider compelling treatment for an adolescent, we need to make absolutely sure we have explored all aspects of the patient’s decision.
     - Have her family and involved clinicians worked to maximize the patient’s quality of life and control any pain or other symptoms?
     - Are there hidden underlying issues the patient is struggling with, such as unrecognized fears, not wanting to impose financial or psychological burdens on her family, spiritual distress, or a special wish that could not be realized if plans for transplantation continue, such as attending a special event in another country?

3. Efficacy of treatment
   - What evidence can we find about the chances for successful outcome with the proposed transplant?
   - How high a chance of success would lead us to attempt to overcome Jane’s refusal to be listed?
   - Would a 50% chance of 5-year survival suffice to justify trying to override Jane’s decision?
   - How does Jane’s age figure into the efficacy discussion?
There are conflicting views among pediatric pulmonologists about long-term survival and quality of life among children with CF who undergo transplantation, compared with those who receive nonsurgical care.

4. Morbidity and mortality of treatment
   - Can we justify a treatment that may prolong her life but ruin her quality of life in the short or long term?

5. Morbidity and mortality of disease
   - What are the options for continued medical management of her disease and what effect would they have on the quality of Jane’s life in the short or long term?

If the adults responsible for Jane’s care conclude that she does not have the maturity to make a fully autonomous decision against additional ICU care and transplantation, what measures could one justify using to ensure future mechanical ventilation or preparation for transplantation? Or, if both parents support Jane’s view, should her doctors seek court-ordered treatment on the grounds that such intervention would serve her best interests?

Defining the legal age of majority at 18 years is an attempt to create conditions in which most patients can participate in the traditional notion of informed consent. This does not imply, however, that no one younger than 18 years can participate in their own health care decision-making. Although most adolescent patients younger than 18 years cannot legally provide informed consent, they can and should provide their assent in decisions that affect their health, life, and death. Parents, physicians, ethics consultants, chaplains, and all involved in conflict surrounding medical decision-making for a minor should do all they can to preserve the integrity of the patient’s participation and the relationships among the patient, family, and members of the health care team. Involving the court system in these cases should always be a last resort. Court intervention disrupts the integrity of the physician-family-patient relationship, affects family privacy, and may hinder future attempts at shared decision-making among the minor, parents, and physician. Moreover, clinicians and the court would have to consider the practical and psychological effect of forced treatment. If Jane resisted surgery, would they find physical or pharmacologic restraint acceptable?

Are there special circumstances in which minors can be legally allowed to make autonomous health care decisions?
1. The emancipated minor
   Under certain circumstances, depending on state legislation and precedent-setting court decisions, minors are deemed emancipated and thereby have sole authority to make health care decisions. These circumstances typically include

   - Minor is living independently and self-supporting.
   - Minor is married.
   - Minor is pregnant or a parent.
   - Minor is in the military.
   - Minor is declared emancipated by a court as described under the mature minor section.

2. Specialized consent statutes
Many states give adolescents independent, confidential, decision-making authority for special health circumstances such as

- Diagnosis and treatment of sexually transmitted infections
- Pregnancy
- Substance abuse
- Mental health services

The nature and scope of these specialized consent statutes vary from state to state.

3. The mature minor
In circumstances in which a minor wishes to make an autonomous decision against the wishes of parents or medical professionals, courts may grant the minor total or partial emancipation (mature minor status) to make decisions. Such court actions are based on existing case law, state statutes, or common law practices and will vary state to state.

*What do we know about adolescent development that helps address the dilemma Jane and her caregivers face?*
Some data (Weithorn and Campbell) suggest that normal 14-year-olds have reasoning power, when considering hypothetical medical situations, equivalent to those legally entitled to make their own decisions at age 21 to 22 years. Other social psychological data (Scott et al) suggest that on average, adolescents have a high tolerance for risk, consider short-term consequences of their acts rather than longer-range ones, and are highly influenced by others, making “independent” mature decisions questionable. Some more recent neuroimaging (Sowell et al) and neuropsychological studies indicate that brain maturation continues well beyond adolescence into the third decade of life.

*Does brain development literature suggest that we should not allow adolescents to make medical (or other important) decisions?*
Brain development in normal situations may not reflect what happens physiologically or psychologically to patients with chronic diseases and with particular medical experiences, such as multiple ICU stays. Some studies (Freyer) suggest a bimodal population of adolescents with life-threatening illness—those who mature beyond their years and those emotionally infantilized by their illnesses. In addition, even if cognitive and emotional development do not fully mature until, say, age 25 years, that does not automatically mean we should prevent decision-making much earlier (Johnson et al). Clinicians should undertake careful individual assessments of cognitive and emotional functioning when asking if any particular child should have decision-making authority.

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