

Session 4. 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) teenagers 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 scientific data indicating caution about this arbitrary age cutoff, we generally uphold 18 as the age of majority, if only for legal reasons. Further complexity enters into this because some, although by no means all, minors 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 birthday.

Instructor's Guide

- Case Summary
- Alternative Cases
- Learning Objectives
- Suggested Reading for Instructor
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Case Summary

Jane developed leukemia at 14 years of age, when she presented with fatigue and bruising. Because she fell into a high-risk category, after achieving remission, she began preparation for stem cell transplantation. She received stem cells from an 18-year-old brother. Now, at 16 years of age, she has had multiple complications of her transplant. She has chronic graft-versus-host disease (GVHD) of her intestines, with intermittent moderate-to-severe abdominal pain. She has moderate renal insufficiency, and in the last 6 months, she twice needed hospitalization in the pediatric intensive care unit (PICU) for respiratory failure, once with

pneumonia and once with a somewhat less clear picture, eventually believed to represent lung GVHD. The second of those episodes of respiratory failure required more than 3 weeks of mechanical ventilation. In addition to needing a ventilator, the PICU staff found it difficult to keep Jane comfortable: she experienced opioid-resistant escalating abdominal pain and periods of severe agitation, requiring complex polypharmacy. Despite use of agents that usually produce amnesia, Jane vividly recalled much of her last PICU stay and repeatedly told her family and health care providers how much she hated the experience. During a clinic visit with the stem cell and palliative care teams, Jane announced that she did not ever want intubation and mechanical ventilation again. She acknowledged that she might survive another episode of respiratory failure. However, she knew that the likelihood of eventual recovery of good gastrointestinal and lung function was small (one of her doctors had quoted a figure of less than 15%). She said she had thought carefully about all her options and conferred with her pastor and concluded that, on balance, she wanted comfort care and no more trips to the PICU. 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 have the legal authority to make autonomous health care decisions?
- How should a physician address conflict between the patient's desired course of medical action and the parents'?

Alternative Cases

1. Sandy, a 14-year-old, has received a diagnosis of Hodgkin lymphoma, with disease above and below the diaphragm. The chemotherapy and radiation that constitute standard treatment carry a high likelihood of leaving her sterile. Her oncologist discusses the possibility of removal of one ovary for cryopreservation prior to her anticancer treatment. Although Sandy has completed puberty, she has no sexual experience and has never contemplated having children. Can Sandy make a mature choice to accept or reject the extra surgical procedure and any other associated risks of ovary removal? If not, should her parents have moral authority to decide this for her?
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, has become 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 relinquish the baby 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 potential additional 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.

Examples from Case Law

In re the Child of Colleen Hauser & Anthony Hauser, 2009 WL 1421504 (D Minn May 14, 2009). Case of a 13-year-old with Hodgkin's Lymphoma IIB whose parents decided they wanted alternative treatment rather than the continued unpleasant side effects of chemotherapy. The boy agreed with his parents.

In re Cassandra C., 316 Conn. (2015). Case of a 17-year-old with Hodgkin's Lymphoma who rejected chemotherapy as "poison."

Benston S. Not of minor consequence? Medical decision-making autonomy and the mature minor doctrine. *Indiana Health Law Review*. 2016;13:1-16.

Learning Objectives

1. Define the circumstances under which a minor would have the legally authority to make autonomous health care decisions.
2. Discuss how the adolescent and brain development literature influences the approach to minors as medical 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 rationale for court intervention.

Suggested Reading for Instructor

American Academy of Pediatrics Committee on Bioethics. Informed consent, parental permission and assent in pediatric practice. *Pediatrics*. 1995;95(2):314-317

Bruce CR, Berg SL, McGuire AL. Please don't call my mom: pediatric consent and confidentiality. *Clin Pediatr (Phila)*. 2009;48(3):243-246

Day E, Jones L, Langer R, Bluebond-Langner M. Current understanding of decision-making in adolescents with cancer: a narrative systematic review. *Palliat Med*. 2016;30(10):920-934

Diekema DS. Adolescent refusal of lifesaving treatment: are we asking the right questions? *Adolesc Med State Art Rev*. 2011;22(2):213-28

Freyer DR. Care of the dying adolescent: special considerations. *Pediatrics*. 2004;113(2):381-388

Katz AL, Webb SA; American Academy of Pediatrics, Committee on Bioethics. Technical report: Informed consent in decision-making in pediatric practice. *Pediatrics* 2016;138(2):e20161485

Wilhelms EA, Reyna VF. Fuzzy trace theory and medical decisions by minors: differences in reasoning between adolescents and adults. *J Med Philosophy*. 2013;38:268-282

Zawistowski CA, Frader JA. Ethical problems in pediatric critical care: consent. *Crit Care Med*. 2003;31(5):S407-S410

Further Reading

Fallat ME, Hutter J; American Academy of Pediatrics, Committee on Bioethics, Section on Hematology/Oncology, Section on Surgery. Technical report: Preservation of fertility in children and adolescents with cancer. *Pediatrics* 2008;121(5):e1461-e1469

Goodman AK. Oncofertility for adolescents: when parents and physicians disagree about egg cryopreservation for a mature minor. *AMA J Ethics*. 2015;17(9):826-833

Johnson SB, Blum RW, Giedd JN. Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *J Adolesc Health*. 2009;45(3):216–221

Mercurio MR. Pediatric obstetrical ethics: medical decision-making by, with, and for pregnant early adolescents. *Semin Perinatol*. 2016;40(4):237-46

McDougall R. The ethics of fertility preservation for paediatric cancer patients: from offer to rebuttable presumption. *Bioethics*. 2015;29(9):639-645

Steinberg L. Does recent research on the adolescent brain development inform the mature minor doctrine? *J Med Philosophy*. 2013;38(3):256-267

Traugott I, Alpers A. In their own hands: adolescents' refusals of medical treatment. *Arch Pediatr Adolesc Med*. 1997;151(9):922–927

Figner B, MacKinlay RJ, Wilkening F, Weber EU. Affective and deliberative processes in risky choice: age differences in the Columbia Card Task. *J Exper Psychol*. 2009;35(3):709-730

Case Discussion

What factors should be considered in allowing a minor to refuse potentially life-prolonging medical treatment?

1. Issues related to basic informed consent
 - 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*?

- Do these factors differ for our patient in important ways as compared to a typical 35-year-old making a similar decision?

2. Why is the patient refusing treatment?

- Have her family and involved clinicians worked to maximize the patient's quality of life and control of 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 respiratory failure developed again soon, such as attending a special event in another country?

3. Efficacy of treatment

- What data would we want about the outcomes of another episode of acute respiratory failure? What constitutes treatment success to the medical team? To the patient?
- What level of efficacy/chance of success, if any, would lead us to attempt to override Jane's refusal of intubation and mechanical ventilation?
- Would a 50% chance of 5-year *survival* suffice to justify trying to override Jane's decision?
- Does Jane's young age in any way alter thinking about the fact that the likelihood of success of treatment for respiratory failure is low? That is—if she survives, she might have a long life ahead of her.

4. Morbidity and mortality of treatment

- Can we justify a treatment that *may* prolong Jane's life but, in her view, do so with an unacceptable quality of life both in the PICU and beyond?

If the adults responsible for Jane's care conclude that she does not have the maturity to make a fully autonomous decision against additional invasive mechanical ventilation and PICU care, what measures could one justify to impose such treatment on Jane? 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 actuate 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 for 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 what they can to preserve the integrity of the patient's involvement and the relationships among the patient, family, and members of the health care team. Turning to the court system in these cases should always be a last resort. Court intervention disrupts the integrity of the physician-family-patient relationship, negatively 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 physically resisted intubation, 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 one or more of the following:

- 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 contrary to the wishes of parents or medical professionals, courts may grant the minor total or partial emancipation (mature minor status) to make decisions. Such judicial actions are based on existing case law, state statutes, or common law practices, and will therefore be determined on a case-by-case basis. Courts often consider the patient's prior experience with his or her medical condition, intelligence, and general evidence of maturity in making these determinations.

Does the brain development literature suggest that we should not allow adolescents to make medical (or other important) decisions?

Brain development in adolescence can be best described as a period of change and evolution in both brain structure and function that extends well-beyond what we typically consider adolescence. There is considerable evidence to suggest that normal 14-year-olds have reasoning and cognitive abilities, when considering hypothetical medical situations, equivalent to those legally entitled to make their own decisions. However, many researchers also describe questions of judgment as influenced not solely by reasoning skills. Typically, adolescents' decisions are highly influenced by social and emotional factors. Emerging evidence from neuroscience indicates that areas of the brain that direct emotional regulation, impulse control, and appraisal of risk/reward in relation to logical

reasoning abilities continue to evolve into the middle of the third decade. As a result, researchers suggest that the differences between adolescents and adults are small in situations where emotional arousal and social influence are controlled (in a hypothetical scenario for example). However, when emotional factors and social influences are heightened, the differences between adolescents and adults are far more pronounced.¹

Therefore, although most agree that reason and cognition often mature early in adolescence, this does not necessarily translate into mature decision making. This should not prevent the possibility of medical decision making by minors, but it should help us better understand the nature of how adolescents may approach medical decisions and what influences their determinations.

What do we know about adolescent development that helps address the dilemma Jane and her caregivers face?

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 PICU stays. Some studies² 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, 25 years of age, that does not automatically mean we should prevent decision making much earlier.³ A number of studies suggest that adolescents do, in fact, seek and in some cases defer to parental help with medical decision-making in the face of serious illness. Clinicians should undertake careful individual assessments of cognitive and emotional functioning and family dynamics when considering whether any particular child should be granted decision-making authority.

References

1. Figner B, MacKinlay RJ, Wilkening F, Weber EU. Affective and deliberative processes in risky choice: age differences in the Columbia Card Task. *J Exper Psychol.* 2009;35(3):709-730
2. Freyer DR. Care of the dying adolescent: special considerations. *Pediatrics.* 2004;113(2):381– 388
3. Johnson SB, Blum RW, Giedd JN. Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *J Adolesc Health.* 2009;45(3):216–221

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