

## ETHICS CASE

### Do Pediatric Patients Have a Right to Know?

Commentary by Philip M. Rosoff, MD, MA

#### Abstract

In Western medicine, a central component of respecting a person's ability to make decisions governing what happens to herself is ensuring that she is provided with sufficient relevant information to make a rational choice. For patients who lack the cognitive capacity to do so because of either inborn or acquired deficits or because of youth, the extent to which they can participate in medical decisions is variable. Minors present a unique challenge, as their ability to understand and process information usually increases with age. The case presented here poses special problems because of the parents' desire to shield their child from certain information deemed important by his physicians. I consider whether minors, particularly older ones, have a right to know that supersedes their parents' wishes.

#### Case

Jenny is a medical student following the care of Adam, a 13-year-old boy who has just been diagnosed with Ewing's sarcoma of the left distal femur. The attending physician, Dr. K, explains to Adam and his parents that the treatment has a very high cure rate and should be started immediately. Dr. K also explains to Adam's parents that Adam will likely be infertile after treatment and that he might not have time to bank sperm. Adam's parents say that they are not interested in sperm banking and request that Dr. K not mention the possibility of infertility to Adam. Adam's father states, "He's too young to understand." Later, Jenny is talking with Adam about his hobbies and aspirations and Adam says, "I can't wait to have a big family one day." Jenny relates this to Dr. K, and he and Jenny discuss Adam's future views about family at length with no mention of the infertility risk posed by Adam's treatment. They also discuss Adam's anger, which often stems from his feeling a lack of control over his life, commonly seen in adolescents with cancer.

Later, Jenny asks Dr. K about whether to inform Adam about the virtual certainty of his infertility due to the chemotherapy he needs. Dr. K says, "His parents understand that Adam needs to be treated immediately and they've clearly stated that they don't want him to know about the infertility risk. We must respect their wishes." Jenny wonders whether Adam could suffer psychologically if he survives his cancer and later realizes he

was uninformed about the treatment's infertility risk. She also wonders whether Adam, who clearly is interested in his future with respect to being a father, has a right to know about this side effect. What, if anything, should Jenny do?

### **Commentary**

Our general understanding of informed consent, based upon the conviction that moral agents have an (almost) unfettered right to control what happens to their bodies, demands that for patients to exercise this power they must have adequate relevant information to make choices they deem appropriate [1]. In order to perform this function adequately, persons must have sufficient cognitive function to both understand and appreciate the potential benefits and harms associated with the proposed intervention and to incorporate this knowledge and their values into a decision. The kind and quantity of information provided can vary, but broadly speaking it must be both satisfactory and materially pertinent such that patients can make an informed choice. For children, the capacity to engage in informed decision making is a gradually acquired capability, and different young people exhibit varying degrees of ability to make informed decisions as they age. The acquisition of the intellectual aptitude to engage in acceptable decision making of this sort correlates with the development of those areas of the brain associated with complex reasoning and forethought, a process that is not complete until the early twenties [2, 3]. Older teenagers and young adults appear to have similar abilities in this domain [4].

At least 14 states recognize the idiosyncratic nature of health care decision making by having so-called "mature minor" laws that can empower certain children, with demonstrable evidence of pertinent faculties (e.g., an understanding of their medical condition and the potential benefits and harms of the proposed treatment) to exercise this authority for themselves [5]. Different professionals—for example, judges or social workers, depending upon the jurisdiction—may be authorized to determine whether a child meets the standard to qualify as an autonomous medical decision maker. In those states in which they are mandated by law to ascertain the case-specific ability of the child, the statutes often specify that the patient must simply meet the "informed consent standard" [5]. In the absence of a court-ordered declaration of emancipation or other mechanism to warrant decisional autonomy—and therefore to be entitled to know all clinically pertinent information associated with the recommended treatment—minors must bend to the wishes of their authorized surrogates, usually their parent(s). While adolescents may be arguably unable to appreciate all of the benefits and burdens of a proposed course of action, they certainly have some appreciation, and engaging them in the decision-making process may be beneficial, although the data to support this are scant [6, 7]. Nevertheless, physicians faced with the situation illustrated by this case can be torn between their beliefs that the child has a "right" to know about a probable side effect that could profoundly affect him in his adult life—and that could be mitigated by an anticipatory intervention such as sperm [cryopreservation](#)—and the desire of his

parents to “protect” him. While the need for initiating treatment may be pressing, as in this case, it is likely that the patient could be offered the opportunity to produce a semen sample if his parents were willing to seriously consider this as an option.

### **Making Decisions for Children**

The sort of problem raised by this case is pervasive throughout the world of [surrogate decision making](#) on behalf of patients who lack capacity, either because of age (children) or cognitive dysfunction, such as that associated with dementia, mental illness, and the like. While few would argue against the reasonableness of respecting surrogates’ discretion in withholding potentially distracting, frightening, or distressing information from those whose intellectual impairment or immaturity is profound (for example, people with advanced Alzheimer’s or five-year-old children), the issue becomes more complicated when the patients clearly have the capability to at least partially understand and appreciate what they have been told and hence should be able to participate to a limited extent in the decision-making (i.e., consent) process. It is often stated by surrogates that they wish to spare their charges the anguish or worry that they might experience when faced with potentially (or imagined-to-be) frightening information [8-11], but it is unclear if these concerns are truly warranted (meaning that children may not be harmed by knowledge of the illness). Unfortunately, many encounters of this type take place with specialists who might not know the patient or her parents all that well and hence may be unable to effectively argue against parents’ refusal to permit the child to participate in discussions about medical care. Nevertheless, it is widely understood and accepted that the preferred model for effective and ethically justifiable medical decision making for both adults and children is one that embraces shared responsibility, involving the parents and child (to the extent she can or wishes to be involved) in a two-way conversation, which can be challenging at times given the differences in family dynamics, the emotional tension of the situation, and so on [7, 12, 13].

Of course, if Adam and his parents lived in a state that permitted adolescents judged to be sufficiently mature to make their own health care decisions (either some or all), then this could complicate matters, especially if he and his parents and his physician were at odds about the appropriate content of and mechanism for delivering important information. If his oncologist believed that it was vital for Adam to know about the potential for infertility and his parents remained adamantly opposed to his knowing, *and* he met the standards for informed consent (however they might be applied and interpreted in his case and jurisdiction), then he could presumably override his parents’ objections. The potential repercussions of doing so could (at a minimum) erode or even rupture trust in this nascent patient-clinician relationship that could ultimately be fatal.

It is also worth noting that many seemingly irrational decisions made by surrogates and patients can stem from misinformation or simply lack of knowledge when a calm, informed discussion could allay their fears and set to rest misconceptions or

misunderstanding [14]. This approach might not always work, however. As the ongoing challenge of parents who refuse to vaccinate their children attests, some people might be immune to this form of rational argument [15, 16]. Moreover, the increasing availability and accessibility of unfiltered and unvetted information obtained from sources on the internet—including websites, blogs, social media networks, and the like—can radically affect the ability of physicians to counter preformed and deeply held beliefs with more reliable and trustworthy data [17-19].

Nevertheless, it is the physician's ethical (and legal) duty to ensure that the responsible consent-granting parties have all the relevant and true information—to the extent possible—needed to make an informed decision [1]. In this case, this would be the parents; the degree to which Adam would be involved and the power granted him to determine what he knows and what happens would be dependent upon his parents' discretionary authority or the state, if they live in a state with a mature minor statute. One final detail is worth noting with respect to legally recognized mature minors. Like other authorized decision makers, minors have a legal right to delegate this prerogative to others (such as their family) if they do not wish to take part in all or some of the decisions that might need to be made [1]. Indeed, if personal autonomy is to have true meaning, autonomous individuals (including mature minors) must be able to grant to others the power to make decisions for them as one instance of an informed choice, although this choice might perhaps be better labelled as a form of shared decision making [20].

A recent report by the Committee on Bioethics of the American Academy of Pediatrics discusses the goals of surrogate decision making:

Surrogate decision-making by parents or guardians for pediatric patients should seek to maximize benefits for the child by balancing health care needs with social and emotional needs within the context of overall family goals, religious and cultural beliefs, and values.... Physicians have both a moral obligation and a legal responsibility to question and, if necessary, to contest both the surrogate's and the patient's medical decisions if they put the patient at significant risk of serious harm [21].

This guidance acknowledges that, in practice, standards of surrogate decision making, whether they are for adults with diminished capacity or for children, involve a complex integration of best interests, family input, and minimizing risk of harm. This is especially the case for pediatric patients who exist, developmentally and cognitively, on a continuum and whose place and role in their family can be constantly changing with time and situation. Some have suggested that a plausible litmus test for the adequacy of a surrogate decision—the bare minimum for what physicians should respect and accept—is what has been termed the “not unreasonable standard,” based in large part on the

kinds of reasons given by the surrogates in support of their choices [22]. Reasons for decisions that could lead to significant harm to the person for whom the decisions are being made must be judged to be sufficiently rational, such that others could not reasonably object [23].

### **Who is Right in This Case?**

Are the parents correct in this case or in others in which parents wish to shield their child from certain information that they believe will be harmful? In my clinical experience caring for children with cancer, it's not unusual for parents to wish for or ask physicians to refrain from telling the patient her diagnosis. In my and others' views, this tendency arises from parents' perhaps mistaken belief that a cancer diagnosis means their child will die and from a belief that their child should be spared the trauma of having the news of a fatal diagnosis revealed [24-26]. In the case, Adam's parents are, probably, similarly motivated by a desire to protect their child from information they believe could be psychologically damaging. However, if Adam's parents' motivation to protect him comes from their belief that he will die, this belief is not based in fact. Indeed, for Ewing sarcoma—Adam's diagnosis—the five-year event-free survival is up to 73 percent [27]. Generally speaking, pediatric clinicians, others caring for those lacking [decision-making capacity](#), and courts have traditionally given great deference to the expressed will of the surrogates unless there is good reason to believe that their decisions could place the patient at risk of imminent harm [28]. However, the meaning of harm has usually been interpreted as "physical," especially in cases such as Adam's [28]. For example, if his parents had refused to give consent for his treatment, it is likely Adam's physicians would have pursued legal action to compel his therapy, and they likely would have been successful due to the risk of significant, life-altering—and, in Adam's case, probably life-ending—harm. But it is doubtful they could make a plausibly compelling argument that, based upon his current statements about his wishes to have a large family, Adam might suffer psychological harm of an incalculable degree sometime in the future, such that this harm would be sufficiently credible to override the parents' authority [29].

There are at least three kinds of potential—and avoidable—related harms that could occur in this case, and while they might be identifiable, their future impact is difficult to quantify. The first is the possibility that Adam would suffer from knowing that he could have had the opportunity to take steps to cryopreserve semen and hence retain a chance (importantly, not a guarantee) to be the biological father of children at some unspecified later time. The second is damage that could be caused by the knowledge that his views and beliefs about what was important to him (the nascent desire to have a number of children as an adult) were ignored or considered insignificant by both his parents and his physician (assuming the latter abided by the demands of the parents to conceal pertinent information from Adam). Finally, Adam will be rendered infertile from physical destruction of spermatogonia due to alkylating agents [30], and, while the biological effects will be anatomic, any negative aftermath will almost undoubtedly be

psychological.

Deliberations about this case depend on how we view and attempt to answer two fundamental questions, assuming that Adam does not live in a state where mature minors may be empowered to make their own health care decisions (and that he would be considered capable of doing so). First, is the physician required to obey the wishes of Adam's parents concerning what happens to their son *no matter what*? Of course that cannot be true, as I have indicated above. However, distinguishing between permissible deviations from medical advice on behalf of others and impermissible deviations is difficult. Technically, Adam's parents' duty within the framework of medical decision making is to act in his best interests—which can be construed as those interests that all children share, such as continued life, and those that may be unique to him, such that only they can define, express, and act upon those interests to protect him from harm. Second, are the putative psychological harms that could occur should Adam not know about his probable infertility and the means to avoid it (sperm-banking) both sufficiently determinable (perhaps as a quantifiable risk) and predictively severe for the physician to attempt to refuse to accept Adam's parents' decision? There are good reasons to believe that effective therapy for Adam's disease will render him infertile. However, future iatrogenic harms that could result from treatments' toxicity are considerably less determinable and hence hypothetical. While it is true that his physician believes he should know about his future infertility, the subjective assessment of hypothetical information on which this belief is based would seem to weigh in favor of the parents' authority. It is also likely that the law would defer to Adam's parents' discretionary authority to keep information from Adam that would seem to fall within their purview to guide and control many aspects of his life.

### **Conclusion**

While I agree that it would be better if Adam knew about this side effect that could affect his life in profound, yet unknown ways, it seems that in this case Dr. K must defer—albeit reluctantly—to Adam's parents' wishes [31]. Nevertheless, it is important that Dr. K convey the reasons why he believes it's important for Adam to know that the treatment almost certainly causes infertility, although I am pessimistic about his chances of altering the parents' views (based upon my personal and my colleagues' clinical experience as well as the lack of consensus on how to alter parental views on childhood vaccinations [32]). The question of whether Adam has a right to know about his condition and the question of how to consider, from a moral point of view, the iatrogenic harms of its treatment are complex ones. Legally, the answer to the question of whether Adam has a right to know is "no." Due to his status as a minor, he is not legally authorized to consent (although many institutions require assent of minors, especially for research participation [33]), and hence he is not entitled to be informed of the benefits and burdens of the proposed therapy as his surrogates (i.e., his parents) are. And it would be unwise to cast his right—legal or moral—in terms of a multitude of

elaborated human rights, only some of which inhere in persons who lack decision-making capacity (such as Adam) [34], as that would potentially distort or even trivialize the moral power that we have accorded rights by amplifying their breadth and scope. We are thus left with a situation that, like so much in health care, is messy and not entirely satisfactory, at least as Adam's physician might view it. It is conceivable that his parents might later regret their decision to withhold information from him, but that, too, like our projections about potential harm to his psychological state, must remain speculative. The bottom line is that, in this situation, the parents' wishes must prevail.

As unsettling to her as it undoubtedly would be, this conclusion also addresses the problem of what the student, Jenny, should do. As torn as she might be, an ethical and legal analysis of this case supports that she should not disclose anything further to Adam. That being said, it would also be incumbent upon the attending physician to discuss the troubling features of this situation and the reasons why he decided to defer to the wishes of the parents despite his (and her) misgivings. It is not uncommon that the most disturbing cases present the best opportunities for learning that clinical practice can be decidedly messy.

## References

1. Faden RR, Beauchamp TL. *A History and Theory of Informed Consent*. New York, NY: Oxford University Press; 1986.
2. Arshagouni P. "But I'm an adult now ... sort of": adolescent consent in health care decision-making and the adolescent brain. *J Health Care Law Policy*. 2006;9(2):315-364.
3. Cohen AO, Casey BJ. Rewiring juvenile justice: the intersection of developmental neuroscience and legal policy. *Trends Cogn Sci*. 2014;18(2):63-65.
4. Steinberg L. Should the science of adolescent brain development inform public policy? *Am Psychol*. 2009;64(8):739-750.
5. Coleman DL, Rosoff PM. The legal authority of mature minors to consent to general medical treatment. *Pediatrics*. 2013;131(4):786-793.
6. Kon AA, Davidson JE, Morrison W, Danis M, White DB; American College of Critical Care Medicine; American Thoracic Society. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188-201.
7. Wyatt KD, List B, Brinkman WB, et al. Shared decision making in pediatrics: a systematic review and meta-analysis. *Acad Pediatr*. 2015;15(6):573-583.
8. Higgs R, Ingram L, Atkin M, Dare J, Neuberger J. A father says, "Don't tell my son the truth." *J Med Ethics*. 1985;11(3):153-158.
9. Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis. *Am J Dis Child*. 1993;147(7):764-768.

10. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med.* 2006;166(5):493-497.
11. Gentry J. "Don't tell her she's on hospice": ethics and pastoral care for families who withhold medical information. *J Pastoral Care Counsel.* 2007;62(suppl 5):421-426.
12. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *New Engl J Med.* 2012;366(9):780-781.
13. Moulton B, King JS. Aligning ethics with medical decision-making: the quest for informed patient choice. *J Law Med Ethics.* 2010;38(1):85-97.
14. Grady C. Enduring and emerging challenges of informed consent. *N Engl J Med.* 2015;372(9):855-862.
15. Dredze M, Broniatowski DA, Smith MC, Hilyard KM. Understanding vaccine refusal: why we need social media now. *Am J Prev Med.* 2016;50(4):550-552.
16. Dubé E, Vivion M, MacDonald NE. Vaccine hesitancy, vaccine refusal and the anti-vaccine movement: influence, impact and implications. *Expert Rev Vaccines.* 2015;14(1):99-117.
17. Fisher JH, O'Connor D, Flexman AM, Shapera S, Ryerson CJ. Accuracy and reliability of internet resources for information on idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med.* 2016;194(2):218-225.
18. Ogah I, Wassersug RJ. How reliable are "reputable sources" for medical information on the internet? The case of hormonal therapy to treat prostate cancer. *Urol Oncol.* 2013;31(8):1546-1552.
19. Winship B, Grisell M, Yang CB, Chen RX, Bauer AS. The quality of pediatric orthopaedic information on the internet. *J Pediatr Orthop.* 2014;34(4):474-477.
20. Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs.* 2014;18(3):273-280.
21. American Academy of Pediatrics Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics.* 2016;138(2):e20161484. <http://pediatrics.aappublications.org/content/138/2/e20161484.long>. Accessed March 27, 2017.
22. Rhodes R, Holzman IR. The not unreasonable standard for assessment of surrogates and surrogate decisions. *Theor Med Bioeth.* 2004;25(4):367-385.
23. Scanlon TM. *What We Owe to Each Other.* Cambridge, MA: Belknap Press; 1998.
24. Parsons SK, Saiki-Craighill S, Mayer DK, et al. Telling children and adolescents about their cancer diagnosis: cross-cultural comparisons between pediatric oncologists in the US and Japan. *Psychooncology.* 2007;16(1):60-68.
25. Badarau DO, Wangmo T, Ruhe KM, et al. Parents' challenges and physicians' tasks in disclosing cancer to children. A qualitative interview study and reflections on professional duties in pediatric oncology. *Pediatr Blood Cancer.* 2015;62(12):2177-2182.



26. Sisk BA, Bluebond-Langner M, Wiener L, Mack J, Wolfe J. Prognostic disclosures to children: a historical perspective. *Pediatrics*. 2016;138(3): e20161278. <http://pediatrics.aappublications.org/content/138/3/e20161278.long>. Accessed April 3, 2017.
27. Womer RB, West DC, Krailo MD, et al. Randomized controlled trial of interval-compressed chemotherapy for the treatment of localized Ewing sarcoma: a report from the Children's Oncology Group. *J Clin Oncol*. 2012;30(33):4148-4154.
28. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243-264.
29. On emotional harms to patients, see Sokol-Hessner L, Folcarelli PH, Sands KE. Emotional harm from disrespect: the neglected preventable harm. *BMJ Qual Saf*. 2015;24(9):550-553.
30. Meistrich ML. Effects of chemotherapy and radiotherapy on spermatogenesis in humans. *Fertil Steril*. 2013;100(5):1180-1186.
31. Clayman ML, Galvin KM, Arntson P. Shared decision making: fertility and pediatric cancers. In: Woodruff TK, Snyder KA, eds. *Oncofertility: Fertility Preservation for Cancer Survivors*. Boston, MA: Springer; 2007:149-160.
32. Eskola J, Duclos P, Schuster M, MacDonald NE; SAGE Working Group on Vaccine Hesitancy. How to deal with vaccine hesitancy? *Vaccine*. 2015;33(34):4215-4217.
33. Grady C, Wiener L, Abdoler E, et al. Assent in research: the voices of adolescents. *J Adolesc Health*. 2014;54(5):515-520.
34. Fortin J. *Children's Rights and the Developing Law*. 2nd ed. Cambridge, UK: Cambridge University Press; 2003.

**Philip M. Rosoff, MD, MA**, is a professor of pediatrics (oncology) and medicine at Duke University Medical Center and Duke University School of Medicine in Durham, North Carolina, where he is also a member scholar in the Trent Center for Bioethics, Humanities & History of Medicine and chair of Duke Hospital's ethics committee. His latest book is *Drawing the Line: Healthcare Rationing and the Cutoff Problem* (Oxford University Press, 2017). His scholarly interest is in the area of the equitable distribution of scarce resources (rationing).

**Related in the *AMA Journal of Ethics and Code of Medical Ethics***

[AMA Code of Medical Ethics' Opinion 2.1.2 Decisions for Adult Patients Who Lack Capacity](#), June 2016

[Can a Minor Refuse Assent for Emergency Care?](#), October 2012

[Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest](#), August 2009

[Ethical Management of Patients with Cancer and Mental Illness](#), May 2017

[Oncofertility for Adolescents: When Parents and Physicians Disagree about Egg Cryopreservation for a Mature Minor](#), September 2016

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.  
ISSN 2376-6980**