

American Medical Association Journal of Ethics

September 2015, Volume 17, Number 9: 826-833

ETHICS CASE

Oncofertility for Adolescents: When Parents and Physicians Disagree about Egg Cryopreservation for a Mature Minor

Commentary by Annekathryn Goodman, MD

Evelyn is 15 and was recently diagnosed with a rare small cell cancer of the left ovary. Although she was able to undergo fertility-sparing surgery with preservation of her uterus and right ovary, metastatic disease was found in the para-aortic nodes at the level of the renal vessels. Her treatment will include pelvic irradiation and six cycles of cisplatin, paclitaxel, and etoposide, all known gonadal cytotoxic chemotherapeutic drugs. Her gynecologic oncologist, Dr. Clark, is familiar with the data on adolescent fertility preservation through egg and sperm banking, a concept known as oncofertility.

Because Evelyn is a minor, Dr. Clark approaches the topic of oncofertility with her parents. Evelyn's mother and father both opposes bringing the topic up with their daughter because they feel she is too young to consider how fertility and infertility would affect the rest of her life and does not have the maturity to make that decision.

Dr. Clark wants to provide the best possible care for Evelyn, and this includes informing her of all the risks and benefits of her treatment. Moreover, he believes that it is his responsibility to present to Evelyn all the possible means of achieving a high quality of life following her treatment. He can't help but think that one day Evelyn will appreciate the fact that she still has the options to have children from her own eggs, even if she ultimately chooses not to do so. He explains his reasoning to Evelyn's parents, but they persist in their decision that Evelyn not be offered the intervention. They ask about the egg retrieval process for oncofertility, and Dr. Clark's answer reinforces their decision. Adding an oocyte retrieval procedure to radiation and chemotherapy is just too much to put Evelyn through, they say.

Commentary

Delivery of medical information and appropriate counseling about medical choices is an essential duty of health care professionals. This case raises important issues about informed consent and the rights of minors to make their own decisions. There is a delicate balance to delivering information to an adolescent patient with a life-threatening condition, counseling concerned and protective parents about medical choices, and advocating for a minor patient when parental decisions are at variance with a physician's recommendation. In this article, I examine the mandate of informed consent and legal views of adolescent decision making, review the long-term fertility

consequences of aggressive oncologic care for the adolescent and young adult, and consider their impact on personal well-being. I examine the ethical dilemma of not disclosing information and the tension between respecting parents' wishes and informing a minor about consequences that will impact her as an adult. In light of these legal, medical, and ethical considerations, I suggest possible solutions for how Dr. Clark can approach both the patient and her family to ensure that a fully informed consent discussion takes place and that respect for the patient's autonomy is preserved.

Informed Consent and the Patient Bill of Rights

Adult patients have a right to receive information about all available treatment options (including no treatment) and the risks and advantages of each before consenting to treatment. A necessary component of informed consent is that patients must understand the consequences of the various options that they may experience long afterward. Informed consent is an essential tenet of patient rights and the standard prequel to any treatment intervention for an adult patient, whether the setting of the medical care is outpatient, inpatient, or an emergency department [1]. Consent is an informed and voluntary decision to proceed with a medical intervention. The decision of a competent person supersedes the advice and recommendations of the doctor. Because patients have the right to determine what happens to their bodies, a doctor cannot touch or treat a patient without that patient's consent.

In the Consumer Bill of Rights and Responsibilities put forth by President Clinton's Advisory Commission on Consumer Protection and Quality in the Health Care Industry [2], information disclosure (chapter 1) and participation in treatment decisions (chapter 4) are central points. Table 1 summarizes information the patient must receive to be considered informed enough to consent. In providing information about the risks and benefits of the recommended treatment intervention, its success rates, and alternative approaches, the clinician must use language that is understandable to the patient, including using interpreters when the patient is not fluent in English.

Table 1. Topics to be covered in an adequate informed consent process

Elements
Description of procedure or treatment
Explanation of risks and benefits
Description of alternative treatment(s)
Description of anticipated outcome if no therapy is given
Description of anticipated short-term consequences of treatment, including length and challenges of recuperation
Description of anticipated long-term consequences of treatment, including permanent alterations to the body

A legal guardian has the duty to decide on medical care when a patient is either incompetent or younger than the legal age of consent, 18 years. This duty derives from the general presumption that parents or guardians will act in the best interest of their children and, legally, from the constitutional right to privacy regarding family matters and the common law rule of parental consent [3].

In the past, minors were not considered legally capable or competent to make medical decisions because of their age [4]. In the past 50 years, the courts have gradually recognized that minors who show maturity and competence deserve a voice in determining the course of their medical treatment [3]. Empirical evidence has revealed that children may be more capable of participating in their medical decisions than previously thought [5]. Legally, the definition of consent requires that an individual give permission voluntarily and with the understanding that he or she is consenting to some form of medical intervention [6]. In addition, the consenting individual needs to cognitively understand and have the ability to explain back the details of the medical intervention. Cognitive development at the ages of 11 to 13 and older correlates with the capacity for legal consent, according to developmental psychological research [5]. [In certain situations](#), depending on the state [7], minors are deemed “mature” and therefore able to consent to treatment without the involvement of a parent or guardian. The “[mature minor doctrine](#)” is the common law rule that allows an adolescent who is mature to give consent for medical care [8]. The assessment of competence is based more on the child’s functional ability than age [9].

“There are also statutory exceptions to the rule of parental consent regarding emergency care, sexually transmitted diseases, drug treatment, mental health care, pregnancy, contraception, and emancipation” for adolescents older than 14 years of age [10]. Table 2 summarizes situations in which a minor has the legal right to make medical decisions [3]. Specific details of the situations in which minors may consent independently to medical decisions vary by state in the United States [7].

Table 2. Conditions allowing minors to consent to medical treatment

Marriage
Past pregnancies
Seeking treatment for: <ul style="list-style-type: none"> • Drug abuse • Alcoholism • Mental and emotional disorders • Sexually transmitted disease • Rape
Being medically screened at a detention center

In the United States, “judges have decided that the ability to consent to a treatment implies the ability to refuse it.... This has led to the development of the concept of ‘assent’” [11]. When children have the cognitive competence “to have some appreciation of a procedure, but not enough competence to give fully informed consent,” they are considered able to “assent” or “dissent,” often around the age of twelve [11]. There are three different categories of consent by minors: consent without their parents’ consent or knowledge; the power to dissent when their parents have consented to their treatment; and the “right to know” even when the minor is not considered competent to make decisions [5, 12].

Reproductive Consequences of Cancer Therapy

Both chemotherapy and radiation can be ovariotoxic and lead to premature ovarian failure [13]. The Childhood Cancer Survivorship Study (CCSS), a large retrospective cohort study following the outcomes and long-term effects of childhood cancer in 5,149 women, found that childhood cancer survivors were less likely than their siblings to ever become pregnant, with a relative risk of 0.81 (95 percent CI, 0.73 to 0.90; $p < .001$) [14].

A range of interventions, from ovarian suppression to surgical transposition of ovaries outside of the radiation field, has been tried to preserve ovarian function [15]. As this case scenario makes clear, one alternative is to preserve ovarian tissue and oocytes for future reproduction in the event that the ovaries lose function. In a center with multidisciplinary resources, fertility preservation procedures will not cause a significant (and perhaps risky) time lag before starting cancer therapy: in a single-institution study in which 96 female patients were referred for oocyte retrieval for cryopreservation [16], the mean time between counseling and retrieval was 15 days. There was no delay in oncologic treatment, with a mean time from laparoscopy to initiation of therapy of 4 days.

Qualitative research on adult survivors of adolescent cancers has identified the profound importance of [addressing fertility concerns](#), which can affect relationships, personal well-being, and life planning [17]. In interviews of 45 adults, cancer therapy during adolescence and its impact on fertility was identified as disrupting personal identities, plans, and values [18]. Findings from in-depth interviews with 38 survivors of adolescent cancers suggest that adolescents can cope with information about fertility options alongside a discussion of cancer [19]. In the same study, women who did not receive fertility services as adolescents reported great distress and regret as adults [19]. Overall, this research has identified the importance of loss of fertility to the disruption of cancer survivors’ personal narratives.

Ethical Considerations

The Declaration of Human Rights identifies the right to a family as a basic human right [20]. Given our ability to preserve cancer patients' fertility, clinicians have a duty to advocate for fertility-preserving measures as part of cancer care.

There is also now significant legal precedent for treating minors with respect, acknowledging their autonomy as persons, and including them in discussions about medical therapies [3, 5, 9-11]. Given the importance of fertility to a person's life plan, the parents' wishes in this case are at variance with the best medical care for Evelyn and her future quality of life. If Evelyn's oocytes can be retrieved and frozen, she will retain the choice to have biological children. If she is not given this option, she may perceive herself as being harmed because her life plans have purposefully been disrupted. A lack of action during the patient's adolescence, specifically not offering fertility preservation options, is a violation of the ethical principle of nonmaleficence.

Finding Solutions

The ideal solution to Dr. Clark's dilemma is to convince the parents that presenting fertility options to Evelyn is the right thing to do. Based on the principle of the "right to know," professional guidelines, and the common law rule, Dr. Clark could consider approaching Evelyn to discuss her treatment options even without seeking parental consent to talk with her [9, 12, 15]. However, without the parents' buy-in to this discussion, there is the risk that they may look for care elsewhere and consequently that Evelyn will not have the opportunity to consider fertility-sparing options. The first step is to explore the parents' concerns fully. Are they just overwhelmed by what Evelyn is facing? Are there any cultural or religious concerns about assisted reproductive techniques? The second step is to get to know Evelyn. What is her understanding about her cancer? What are her hopes and dreams about her future? From these conversations, Dr. Clark will be able to assess Evelyn's cognitive and decision-making abilities. He might also refer the family for a consultation with a clinician at another institution because second opinions can help clarify issues, confirm treatment recommendations, and potentially explore different treatment options [21].

When there is potential conflict with the legal guardians of a patient, it is important to bring in help and not negotiate alone. Various consultative services are available at cancer centers such as the ethics committee, social services, chaplaincy, and adolescent medicine specialists. A family meeting with several specialists may help to address the parents' concerns and provide expert guidance. In addition, other adolescent patients and their parents who have been through both cancer therapy and fertility preservation may give vital peer-to-peer support and advice. Resources Dr. Clark can draw upon are listed in table 3.

Table 3. Resources for conflict resolution with parents

Medical
<ul style="list-style-type: none">• Adolescent medicine• Reproductive endocrinology• Psychiatry• Palliative care
Supportive services
<ul style="list-style-type: none">• Social services• Chaplaincy
Hospital services
<ul style="list-style-type: none">• Legal council• Ethics committee
Peer group support
<ul style="list-style-type: none">• Parental peers• Adolescent peers

Conclusion

One of the pillars of health care is to respect the autonomy of the patient by obtaining informed consent to treatment. Minors deserve special protection but are also entitled to basic rights. They are increasingly autonomous, both developmentally and in legal terms, from 11 to 18 years of age [5]. When a clinician and the parents of a minor patient disagree about providing the patient with all the options for future fertility, a multidisciplinary intervention should be considered. The best possible outcome of both cancer treatment and fertility preservation can be realized for an adolescent patient with counseling, education, and peer support.

References

1. Goldman EB, Annas GJ. Patient rights. *Law Med Health Care*. 1981;9(4):36.
2. President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry. *Quality First: Better Health Care for all Americans*. March 30, 1998. <http://archive.ahrq.gov/hcqual/final/>. Accessed July 10, 2015.
3. Hickey K. Minors' rights in medical decision making. *JONAS Healthc Law Ethics Regul*. 2007;9(3):100-104.
4. Zawistowski CA, Frader JE. Ethical problems in pediatric critical care: consent. *Crit Care Med*. 2003;31(5)(suppl):S407-S410.
5. Grisso T, Vierling L. Minors' consent to treatment: a developmental perspective. *Prof Psychol*. 1978;9(3):412-427.
6. Waltz JR, Scheuneman TW. Informed consent to therapy. *Northwest Univ Law Rev*. 1970;64(5):628-650.
7. Vukadinovich DM. Minors' rights to consent to treatment: navigating the complexity of state laws. *J Health Law*. 2004;37(4):667-691.

8. Appelbaum PS, Lidz CW, Meisel A. *Informed Consent: Legal Theory and Practice*. New York, NY: Oxford University Press; 1987.
9. Osuna E. Legal protection of informed consent of minors. *Med Law*. 2010;29(2):217-226.
10. Sigman GS, O'Connor C. Exploration for physicians of the mature minor doctrine. *J Pediatr*. 1991;119(4):520.
11. Foreman DM. The family rule: a framework for obtaining ethical consent for medical interventions from children. *J Med Ethics*. 1999;25(6):491.
12. LoCicero A. The right to know: telling children the results of clinical evaluations. In: Koocher GP, ed. *Children's Rights and the Mental Health Professions*. New York, NY: Wiley; 1976:13-21.
13. Iorio R, Castellucci A, Ventriglia G, et al. Ovarian toxicity: from environmental exposure to chemotherapy. *Curr Pharm Des*. 2014;20(34):5388-5397.
14. Green DM, Kawashima T, Stovall M, et al. Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2009;27(16):2677-2685.
15. Ethics Committee of American Society for Reproductive Medicine. Fertility preservation and reproduction in patients facing gonadotoxic therapies: a committee opinion. *Fertil Steril*. 2013;100(5):1224-1231.
16. Sigismondi C, Papaleo E, Viganò P, et al. Fertility preservation in female cancer patients: a single center experience. *Chin J Cancer*. 2015;34(1):56-60.
17. Crawshaw M. Psychosocial oncofertility issues faced by adolescents and young adults over their lifetime: a review of the research. *Hum Fertil (Camb)*. 2013;16(1):59-63.
18. Barbour RS, Porter MA, Peddie VL, Bhattacharya S. Counseling in the context of fertility and cancer: some sociological insights. *Hum Fertil (Camb)*. 2013;16(1):54-58.
19. Crawshaw MA, Glaser AW, Hale JP, Sloper P. Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *Eur J Cancer Care (Engl)*. 2009;18(4):381-390.
20. United Nations. The Universal Declaration of Human Rights. <http://www.un.org/en/documents/udhr/>. Accessed July 17, 2015.
21. Goldman RE, Sullivan A, Back AL, Alexander SC, Matsuyama RK, Lee SJ. Patients' reflections on communication in the second-opinion hematology-oncology consultation. *Patient Educ Couns*. 2009;76(1):44-50.

Annekathryn Goodman, MD, is an associate professor of obstetrics, gynecology, and reproductive biology at Harvard Medical School in Boston and the director of the gynecologic oncology fellowship program and a member of the ethics committee at Massachusetts General Hospital in Boston. She is board certified in gynecologic oncology and acupuncture and has completed training in both pastoral and palliative care. Dr. Goodman is a fellow of the American College of Surgeons and the past president of the

Obstetrical Society of Boston and of the New England Society of Gynecologic Oncologists.

Related in the *AMA Journal of Ethics*

[Communicating Risk of Infertility to Adolescents Prior to Chemotherapy](#), August 2009

[Withholding Information from an Adolescent](#), August 2008

[Presymptomatic Testing of Children for Huntington's Disease](#), September 2009

[Minors' Right to Know and Therapeutic Privilege](#), August 2013

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 2015 American Medical Association. All rights reserved.
ISSN 2376-6980**