

Chapter 15

Ethical Dilemmas in Oncofertility: An Exploration of Three Clinical Scenarios

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Introduction

As an emerging interdisciplinary field, oncofertility bridges oncology, reproductive endocrinology, and infertility with the goal of expanding reproductive options for women with cancer. Oncofertility is currently gaining significant attention from professionals in many related fields and is undergoing considerable scrutiny in part because of the many compelling ethical dilemmas it raises. To illustrate some of the dilemmas providers face, and make suggestions for clinical care, this chapter presents three clinical scenarios encountered in medical practice. An increased awareness of the complex problems involved should help prepare clinicians for some of the challenges posed by this rapidly expanding discipline.

While the three cases presented here are based on real-life situations, they have been modified to protect the identity of the patients involved. The cases raise the diverse, and sometimes overlapping, problems that surface in the clinical environment, highlighting different ethical dilemmas faced by physicians. For the sake of brevity, we have chosen to explore only two problems in each of the first two cases and one in the third. Each dilemma is presented in the form of a question to capture a central point, although in fact the cases are complicated and involve many variables. Two alternative courses of action in each case appear unavoidable but also unacceptable, creating a seemingly unresolvable situation for the clinician. The question is what can physicians do under these circumstances to satisfy the requirements of their ethical responsibility? Can they escape the pitfalls of the dilemmas and find ethically satisfactory courses of action?

After presenting each of the three cases, we discuss them and highlight the dilemmas they pose. We then present three theoretical strategies commonly used in ethics. Two of these, deontology and consequentialism, fail to resolve the dilemmas, but a third, namely virtue ethics, appears promising. Finally, we suggest some practical steps that should help physicians move closer to a resolution of their quandaries.

Case 1: Description

Alice is a 15-year-old Chinese American female with a history of Hodgkin's lymphoma who was found to have recurrent lymphoma several months after chemotherapy. A bone marrow transplant had been advised by her oncologist, a treatment that would almost

certainly result in permanent infertility. While her oncologist had discussed this risk with her parents, neither the physician nor her parents had discussed the risk with Alice or had given her the option of pursuing methods to preserve her fertility. However, a day before her scheduled bone marrow transplant, she learned through the internet that the procedure would likely render her sterile. She then confronted her parents and physicians and asked if she could pursue fertility preservation options. Ultimately, she was referred for a fertility preservation consultation and banked ovarian tissue. Unfortunately, because of the late decision to proceed with fertility preservation and limited availability at the transplant center, her bone marrow transplant was significantly delayed, with the potential to worsen her long-term prognosis.

Who Should Make Decisions in Adolescent Medical Care: Adolescent Patients or Parents?

It is generally believed that a therapeutic patient–physician relationship consists of a partnership in which both parties participate actively to make medical decisions. “Patients have a right to know about their health, to know about available diagnostic and treatment options and their risks and probable benefits, and to choose among the alternatives” [1]. While these principles apply to competent individuals at least 18 years of age, the role of the adolescent patient in medical decisions remains ambiguous primarily because the United States legal system generally does not give adolescents autonomy unless they are considered emancipated minors, mature minors, or are seeking treatment for specific disorders [2]. Patient autonomy is commonly understood to mean that a patient has the capacity to act intentionally, with understanding, and without controlling influences that undermine a free and voluntary act. This principle is at the basis of “informed consent” in the physician–patient transactions regarding health care.

Because there is evidence that most minors age 15 and older are able to understand concepts about treatment alternatives and provide informed consent, the American Academy of Pediatrics has recommended that physicians involve adolescents in the medical decision making process [1–3]. Adolescents are generally asked to provide “assent,” an indication that they are participants in the process, although they do not have absolute autonomy in decision making. However, it is not always the case that adolescent patients are fully informed of all of the risks, benefits, and alternatives of treatment so that satisfactory decisions can be made.

The reality of clinical practice is that adolescents are often not informed of the reproductive consequences of cancer therapy and potential options to mitigate these long-term effects [4, 5] because physicians feel they need to defer to the authority of parents/guardians. In our case, while Alice’s parents were fully informed of all of the reproductive risks of the recommended cancer treatment, the patient was not. Reasons for nondisclosure may include a primary focus on curing the cancer rather than on long-term quality of life, a desire to protect the child from anxiety, discomfort in discussing sensitive issues such as future sexuality and childbearing, and the limitations of fertility preservation methods. One study reports that about half of the physicians interviewed said that the cancer diagnosis causes such shock that issues like fertility are often put on

the “back burner” [4]. Infertility is generally not emphasized as a major risk of cancer therapy and therefore does not get the same attention as other health risks such as cardiac damage, cognitive impairment, or new malignancies; it simply is not something patients and family members think of when cancer is diagnosed [6]. A survey of teens and young adult women undergoing cancer treatment reports that a minority of these young patients are satisfied with the information they received about cancer-related infertility from their oncology team and a third to half of the teens cannot recall any discussion of such topic [7].

Failure to disclose such information to adolescents prevents them from participating in decision making. In Case 1, nondisclosure led to a significant delay in life-saving cancer treatment because the patient wanted to pursue fertility preservation. On the one hand, given that fertility preservation technology is becoming more widely available and publicized [8], failure to discuss these options might lead to substantial future anger and resentment toward parents and physicians. On the other hand, overemphasis on reproductive consequences and lack of appropriate follow-up leads some adolescents to assume that their treatments have left them infertile. This in turn prompts them to stop using contraception, which can result in unplanned pregnancies [7].

Should a Physician Abide by or Reject Different Cultural Traditions with Respect to Disclosure and Medical Decision Making?

The cultural perspectives of patients and families can also influence the patient–physician relationship. The Chinese cultural background of the family depicted in the clinical scenario in this case may have played a major role in the communication barriers that occurred between the individuals involved. Although in East Asian cultures, especially those of Japan and China/Taiwan, the concept of telling the truth is highly valued, the situation is different in the context of serious medical conditions [9–11]. In these Asian countries, a “family consent for disclosure” is commonly adopted as a way of transmitting information in a health context, where a physician must respect the family’s wishes and often act on the family’s accord in the treatment of a patient [10]. Consistent with Chinese culture, many believe that in serious illnesses, revealing the diagnosis to patients results only in hopelessness and may actually hinder recovery [12, 13]. Among members of these cultures or ethnic groups, families do not consider nondisclosure to the patient to be morally objectionable, but rather perceive it as a form of protection [9]. Physicians often reveal the complete diagnosis only to the families, whose members have the primary responsibility to disclose to patients what they deem appropriate. Although this is quite contrary to modern mainstream medical practice in the United States, where full disclosure and informed patient consent by physicians to patients is the norm, much of the rest of the world continues the cultural practice of nondisclosure in medically serious conditions.

In Case 1, the parents may have concealed aspects of their child’s diagnosis and treatment because they believed that informing her of all the risks of her illness and treatment would be detrimental to her recovery. They acted on what they considered to be the best interest of their daughter, rather than telling her the truth about her condition and

the risks for future childbearing. This lapse in the proper transmission of information from the Western point of view between the parents and the child would not have been problematic had the child shared the values of her parents. However, this was not the case, for the patient became extremely concerned with her treatment upon learning of its risks for future childbearing. Such differences in opinion between parents and adolescent children may be due to generational and/or cultural gaps that exist [14]. Whereas the parents still identified principally with Chinese culture, the Chinese-American daughter had been raised in a vastly different environment, with different social values. The ethical dilemma for physicians facing such clinical situations lies in whether they should respect the cultural norms of parents and allow them to decide what information to disclose to their teenage children or to enforce full disclosure. Undoubtedly it can be challenging for physicians to refuse the wishes of parents who feel that they have their children's best interest in mind, sincerely believe that their approach is the best, and have cultural traditions dating back hundreds of years.

Case 2: Description

Lisa is a 32-year-old recently married woman diagnosed with metastatic breast cancer. Prior to her cancer treatment, she pursued IVF and banked nine embryos. Unfortunately, despite aggressive cancer therapy, she died a year later. The embryos were left at her husband's discretion and initially he was unable to make a decision about disposition. He did not wish to have the embryos placed in a gestational carrier, donate them to another couple, discard them, or continue paying for storage. He has not paid for storage for 6 months and now the clinic cannot reach him.

Should Cancer Patients with Poor Prognosis Be Allowed to Pursue Fertility Preservation or Should They Be Denied Treatment?

Most females of reproductive age with cancer have an excellent chance of survival and many will eventually be healthy enough to use cryopreserved gametes and embryos [8, 15, 16]. Moreover, since having biological children is highly valued and important for long-term quality of life for many individuals, fertility preservation can be justified in most cancer patients of reproductive age. However, there are situations, such as the one in Case 2, in which patients have a very poor prognosis and may never have the opportunity to use the gametes or embryos. One might argue, based on considerations of fairness, that it is an unwise utilization of resources to allow cancer patients with low likelihood of survival to pursue methods of fertility preservation insofar as it is very likely that the embryos would remain unused and those resources could be better used by others. Another argument against fertility preservation in a case such as this is that the procedure may instill an unrealistic sense of hope in patients, and this might be detrimental because it may prevent patients from accepting the severity of their illness. A contrasting view is that providing patients with a sense of control and hope may actually be therapeutic and help them cope with the illness. Fertility preservation might also be important for partners and family who wish to keep the memory of a loved one alive through a future child. Finally, denying care based on prognosis can be difficult because it requires clinicians to draw a line on eligibility. What should be the estimated prognosis

of a patient in order to offer fertility preservation, and who will determine the prognosis especially when there is limited data available?

Should Physicians Discard Abandoned Frozen Embryos and Gametes or Continue Their Cryopreservation?

The questions surrounding the treatment and storage of frozen embryos are not unique to oncofertility, as excess embryos are stored routinely as part of in vitro fertilization (IVF) for the treatment of infertility. A 2007 survey conducted by the American Society for Assisted Reproductive Technology estimated that over 400,000 frozen embryos were being held in cryopreservation storage facilities in the United States [17]. As fertility preservation becomes more available, there will be an increasing number of embryos and gametes in long-term storage facilities and IVF clinics. In oncofertility, it is anticipated that not all gametes and embryos will be utilized to achieve a pregnancy since cancer patients may die, conceive on their own, or decide not to pursue childbearing. Moreover, the long lag time between cryopreservation and clinical use increases the potential for loss of contact and therefore makes embryo and gamete abandonment likely as well. The potential for unclaimed frozen embryos and gametes in storage facilities raises ethical problems. Couples generally state their wishes regarding embryo disposition in writing prior to storage. They are given three options in case of death of each parent: donation to research, donation to another couple, or destruction. However, often little attention is given to this process, especially when patients are overwhelmed with a recent cancer diagnosis and are rushing to pursue fertility preservation methods prior to cancer treatment. The focus is on curing the patient and preserving future fertility, rather than planning on case of death. Case 2 illustrates how difficult it can be to decide on disposition of embryos after the death of a spouse. In this case, rather than make a decision, the husband abandoned the embryos.

In situations in which the partners are uncomfortable with the three options mentioned and prefer to keep the embryos in storage, even though they are not willing to pay for the cost, is it ethical to discard the embryos? The position of the Ethics Committee of the ASRM is that it is reasonable to destroy embryos “if more than 5 years have passed since contact with the couple, diligent efforts have been to contact the couple. . . and no written instruction from the couple exists concerning disposition” [18]. Still, although it might be reasonable and legally defensible to discard such embryos and gametes, many IVF clinics feel uncomfortable with this practice and continue to store abandoned embryos indefinitely insofar as they feel the embryos have intrinsic value [19]. While the disposal of abandoned gametes and ovarian tissue may be considered less problematic because these are generally not given moral status, there is no question that these tissues also have value insofar as they represent the potential for a future biologic child.

Case 3: Description

Michelle is a 28-year-old patient with severe mixed connective tissue disease and multiple medical problems including pulmonary hypertension. Due to the severity of her illness, she had been advised to pursue an experimental regimen normally used to treat

cancer that included high dose gonadotoxic chemotherapy as well as a bone marrow transplant. Michelle is a highly educated individual and had done extensive research regarding this treatment and understood the almost certain risk of future infertility and premature ovarian failure. Therefore, she was intent on banking eggs prior to treatment even though she realized that she might never be healthy enough to carry a pregnancy and would need to use a gestational carrier. After being medically cleared by her physicians, she underwent ovarian stimulation and 12 mature eggs were successfully frozen. However, 2 days following the fertility preservation (FP) procedure, she was admitted to the hospital with high fever and respiratory distress and had a complicated hospital stay due to the severity of her mixed connective tissue disease. Her recovery was very slow and ultimately she had to delay the treatment of her underlying disease.

Should Patients with Medically Complicated Conditions Be Offered or Denied Methods to Preserve Fertility?

As fertility preservation methods become more widely available, demand is increasing even among patients without cancer who suffer from other conditions that might affect future fertility. This phenomenon has broadened the application of fertility preservation techniques to many medically complicated patients who would not normally pursue these procedures and, like the patient in Case 1, place a very high value on the potential to have a biologic child in the future. Unlike most young women with cancer or infertility for whom these procedures pose very little risk, these procedures can involve significant health hazards in medically complicated patients. Indeed, as in the scenario described in Case 3, proceeding with ovarian stimulation and egg banking can result in many serious complications, even death. The risks and benefits of fertility preservation procedures can be difficult to balance, particularly in cases such as Michelle's, because it is not clear what the actual risk might be to the patients' health. In Michelle's case, had the physician known that she would become critically ill after the procedure, thus delaying potentially life-saving treatment, then it would have been ethically justifiable to deny her fertility preservation options. However, her poor outcome was not foreseeable. And, although alternatives such as adoption may appear to be an excellent long-term solution for having a family in the future for such patients, it must be recognized that the illness itself might prohibit the women from adopting children so that this option may not actually be a viable alternative (See [Chapter 34](#) by Gardino and Emanuel in this book). So how should physicians better counsel patients and establish rules of consent for fertility procedures in patients who have complicated medical conditions and for whom there is no safety data? Can a clear line of eligibility be drawn? And when should patients be excluded from fertility preservation options due to their health?

Theoretical Strategies

Ethicists have developed a number of strategies in response to these matters, none of which is universally accepted or above criticism. From the many available, we have chosen three to illustrate how they attempt to escape the dilemmas considered here. Two of these are quite popular, but in the end do not appear to work well in the cases we have

discussed. They go by the names of *deontology* and *consequentialism*. The third, known as *virtue ethics*, has more promise [20].

According to the deontological strategy, in order for actions to be ethically sound, they must be made on the basis of principles that are worthy in themselves, apart from any consideration of the consequences that those actions may have. In Case 3, for example, the autonomy of the patient is a good in itself and as such must be respected by the physician, even if the patient uses her autonomy to reach decisions that will cause her harm. *Prima facie*, this approach appears to dissolve the quandary of the physician. In spite of the patient's condition and any possible outcomes, the physician must honor the patient's autonomy, and thus implement her wishes. In doing so the physician acts ethically.

Although this course of action sounds both idealistic, insofar as the physician acts according to principle, and convenient, insofar as the physician's role and responsibility are clearly defined, the situation is not as simple as it appears. Two problems make this clear. The first is that there are more than one principle at play in this situation. Certainly the Principle of Autonomy is a worthy one, but there is also the Principle of Nonmaleficence, which states that a physician should not cause harm to a patient. And if the physician knows that the procedure the patient wishes to have is likely to cause her harm, then the physician must choose between the two principles, thus still facing an ethical dilemma.

The second problem is that it makes no intuitive sense to argue that the ethical value of an action relies fundamentally on a matter of principle and has nothing or little to do with its consequences. Indeed, is it not a matter of common sense that we judge many actions to be morally reprehensible precisely because they cause harm? Can we really hold that an action that causes no harm at all is as morally bad as one that causes harm? It seems to make little sense to talk about the worth of principles apart from consequences in a medical context in which the whole enterprise is predicated on weighing what is better or worse for patients.

It is problems such as these that lead other ethicists to reject deontology and defend consequentialism instead. This strategy argues that the ethical value of actions should be measured exclusively by their consequences. If fertility treatment in a cancer patient has better results than no treatment, then the decision to treat the patient is ethically sound. But if its consequences are worse than no treatment, then the decision to proceed with the treatment is ethically unsound. The value of this approach is that it brings back into the picture the benefit of the patient. For Case 1, if respecting the culture of the parents, and not informing the patient of the consequences of her treatment, results in harm to the patient, namely, permanent future infertility, then the decision is ethically unsound. Physicians, so the argument goes, need to focus on the results of the procedures they recommend, rather than on the ideal worth of any abstract principles they may use.

However, this strategy also runs into difficulty on many counts, two of which are quite evident. The first is that the consequences of the actions taken by physicians regarding

treatment of their patients are often not known to the physicians prior to the treatment. This is evident in Case 3, where the condition the patient developed after infertility treatment was only a possibility among many, and became a reality only after the treatment was implemented. How can a physician determine and choose the ethically sound decision before he or she knows what will actually happen to the patient? Patients are unique in many ways and their health is affected by many variables, some of which are not measurable and unknown at the time a decision concerning a treatment must be made. For this reason, it makes no sense to base ethical responsibility on factors that lie outside the information accessible to a physician.

The second problem with consequentialism is that it is quite impossible to measure all the consequences of any action. The actions physicians take have innumerable consequences. Some of these affect the patients, but others affect other people, such as partners, members of families, and even society at large. This is quite evident when we consider such things as the cost of egg preservation over the long run, as we saw in Case 2. And who can measure all these consequences? How can a physician be expected to act ethically, if the ethical value of the action is contingent on such an innumerable, and mostly unavailable, number of consequences of the actions?

In short, consequentialism does not help physicians resolve the dilemmas posed by the three cases we have examined. Indeed, neither consequentialism nor deontology offers effective guidance in resolving them, and in some ways, they make matters worse.

This leaves us with the strategy we think has the most promise, the virtue ethics option. According to this point of view, the key element in the resolution of ethical dilemmas such as the ones physicians face in the three cases presented here, is the physicians themselves. Principles and consequences are important only to the extent that they play a role in the deliberations in which physicians engage prior to their decisions. Ultimately, physicians determine the best course of action. This makes physicians, their training, and their character, essential in medical ethics and underscores the need for their proper training and education, not only in physical diseases, but also in mental health, social issues, and ethics. The authority of physicians is based on their accumulated knowledge and experience. A virtue ethics approach does not entail a free ride for physicians, or a view that whatever they do is right. In fact, this approach puts a heavy burden on them to accept and exercise their responsibilities with utmost care, based on sound practice.

This position is called virtue ethics because it bases ethical behavior on what a person with the proper training and education would do, which in this context refers to the physician. Of course, not all physicians are equally well trained or educated, or have the proper experience, a reason why consultation among physicians is essential, as is the supervision of younger physicians by older ones. There is no substitute for experience. If you want your kitchen faucet fixed, it is better to have someone who has fixed 1,000 kitchen faucets do it than to have someone who can describe how to do it well, but has never fixed one. Likewise, it is the physician in the field, the one who has experience of many cases, who is most competent to decide the course of action in any particular case.

What makes these decisions particularly challenging in a new field like oncofertility is that physicians with long-term experience are scarce.

The virtue ethics approach has a number of advantages over the two others we have considered. One advantage is that it incorporates the other two theories insofar as properly trained physicians will consider consequences, as far as they can be known, as well as principles. Another is that it gives physicians the authority to act, with full knowledge that sometimes outcomes may not be ideal. And a third is that it individualizes decisions, focusing on the particularities of the cases. An experienced physician with the proper training should be able to broker a deal between the ethnic parents and the adolescent of Case 1, determine what is best in terms of treatment for the seriously ill patient of Case 2 and her preserved eggs, and judge the right course of action when it comes to the treatment of the patient with the medically complex condition of Case 3. To repeat, this approach does not absolve physicians from responsibility, but rather it recognizes their authority and gives them the freedom to act according to their best judgment and without regret.

Practical Strategies

Apart from the theoretical strategies discussed above, there are some practical steps that help physicians deal with the dilemmas they face in the practice of oncofertility. Moreover, they fit well with the virtue ethics approach we have suggested insofar as they require a case-by-case and individual approach, based on experience and training. We offer first some general guidelines that apply throughout the practice of the discipline and then we turn to specific recommendations that apply to the cases presented here.

First, physicians must be keenly aware of the particular kinds of problems reflected in these clinical scenarios, for it is ultimately the responsibility of physicians to recognize and address these problems before any treatment is initiated. Second, a team approach to counseling is most helpful, in which reproductive endocrinologists, oncologists, nurses, and mental health professionals discuss fertility preservation options over several visits if time permits. This allows for a more comprehensive evaluation to explore and understand family dynamics, values, and cultural issues. And third, understanding a patient's perspective is critical in establishing a therapeutic patient–physician relationship in which both parties not only discuss the risks, benefits, and alternatives of fertility preservation, but long-term prognosis, and disposition of tissues.

Specific Suggestions for Case 1

Who Should Make Decisions About Adolescent Medical Care and to What Extent Should Cultural Factors Play a Role in Informing Patients of Their Condition?

This case highlights how the ethical dilemmas faced by physicians taking care of adolescents with cancer are largely the result of communication barriers between physicians, the patients' parents/guardians, and the patients themselves. Removing such

barriers through enhanced physician awareness and comprehensive communication is an effective way for physicians to tackle the dilemmas in this situation [5].

In adolescent cases, physicians should work to establish close relationships with both patients and their parents/guardians so that true, shared decision making can take place [14, 21, 22]. It is important to include adolescents in the conversation and listen to their perspectives. Such an approach should allow all parties to discuss the options openly and come up with solutions that are acceptable to everyone. Since every situation is unique, counseling should be individualized. The cultural/ethnic background of the patients and potential disparities between the point of views of families and patients must be taken into account, but ultimately should not interfere with establishing a therapeutic relationship between the physician and patient. If differences in opinion occur between parents and minors, then physicians should serve as mediators and try to balance the autonomy of the minors, the best interests of the minors, the parents' values, and the law. Legal intervention should be a last resort [2].

Specific Suggestions for Case 2

Should Cancer Patients with Poor Prognosis Be Allowed to Pursue Fertility Preservation?

Physicians should take into account the long-term prognosis of patients when counseling about fertility preservation. An open and honest discussion of the potential for survival and pregnancy not only helps in the decision making process, but also prepares patients for their treatment and helps them to consider the future realistically. It is our experience that many such patients will decide against fertility preservation after a thorough discussion has taken place. Nonetheless, we do not believe that strict criteria should be applied to prognosis since this is often not practical. Consultation and collaboration with the oncologist will help guide these discussions. Even if the prognosis is poor, a patient's wishes should not be altogether ignored. Counseling should be provided throughout, and fertility preservation may be considered as long as the patient has a full understanding of her situation and the potential risks involved [21].

What Should Be Done with Abandoned Frozen Embryos and Gametes?

To prevent uncertainty about gamete and embryo disposition, it is critical that physicians fully address this issue before performing any fertility preservation procedures. A clear understanding and documentation of the wishes of cancer patients and their partners must take place. This should include instructions concerning the "disposition in case of death, divorce, separation, failure to pay storage charges, inability to agree on disposition in the future, or lack of contact with the program" [18]. Clear instructions on disposition in case of abandonment can help to prevent the ethical dilemma of embryo and gamete disposition. Because cancer patients may store tissues for long periods, even decades, it is important that IVF clinics maintain regular contact with patients. These steps do not always absolve physicians from the dilemmas posed by Case 2, but they do ameliorate the situation and help physicians fulfill their ethical responsibilities. Consultations with a

mental health professional concerning patient and partner preferences for disposition should also be encouraged.

Specific Suggestions for Case 3

Should Patients with Medically Complicated Conditions Be Offered Methods to Preserve Fertility?

Physicians must strike a delicate balance between the patient's autonomy and minimizing risks to the patient. As with the previous cases, establishing a strong relationship between the patient and physician will allow for an open discussion of potential risks, benefits, and alternatives to treatment. Since a reproductive endocrinologist does not have the requisite experience to manage patients with complex medical problems, it is important to seek recommendations from physicians caring for the patient and perhaps ask for additional pertinent opinions. In the clinical scenario presented in this case, understanding the patient's motivation for pursuing the procedure is also important because she was informed of the low probability that she would ever be able to carry the pregnancy and most likely would have to use a gestational carrier but still insisted on the fertility preservation treatment. The physician must make sure that the patient's resolve in cases such as this is not an indication that she does not fully grasp the severity of her situation. Psychosocial counseling is invaluable in such cases in order to ensure that the patient has decisional capacity and is making a reasonably informed choice. In cases where a physician feels that the risk outweighs the benefit, it may be necessary to deny care or refer the patient to another provider. When physicians are undecided about how to proceed, it may be helpful to seek advice from an ethics committee.

Conclusion

The theoretical approach and practical steps suggested in the three cases we have discussed should help physicians deal with some of the ethical difficulties they face in making decisions about patients in the field of oncofertility. In particular, the emphasis on communication, counseling, development of awareness of cultural background, considering patient prognosis, and collaboration with other allied health providers should help resolve some situations and lead physicians to reach reasonable decisions and make good recommendations. However, these steps do not completely eliminate the dilemmas physicians face. As demonstrated in the three cases we have presented, physicians have to make decisions to the best of their ability, even though these choices may not be acceptable to all parties involved or completely beneficial for all. In short, the ethical dilemmas do not disappear completely and it is the duty of the physician to weigh the risks, benefits, and wishes of patients and families to guide them to the best course of action. Ultimately, a better understanding of the complex ethical, social, and medical issues in oncofertility is needed. As this field grows, continued multi-disciplinary research and clinical experience will help to inform good clinical practice.

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References

1. Committee on Bioethics, American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995; 95(2):314–7.
2. Kuther TL. Medical decision-making and minors: issues of consent and assent. *Adolescence*. 2003; 38(150):343–58.
3. Melton GB, Koocher GP, Saks MJ, Eds. Decision making in children: psychological risks and benefits. Children's competence to consent. New York: Plenum; 1983:21–40.
4. Quinn GP, Vadaparampil ST. Fertility preservation and adolescent/young adult cancer patients: physician communication challenges. *J Adolesc Health*. 2009; 44(4):394–400.
5. Quinn GP, et al. Patient-physician communication barriers regarding fertility preservation among newly diagnosed cancer patients. *Soc Sci Med*. 2008; 66(3):784–9.
6. Schover LR. Patient attitudes toward fertility preservation. *Pediatr Blood Cancer*. 2009; 53(2):281–4.
7. Zebrack BJ, et al. Fertility issues for young adult survivors of childhood cancer. *Psychooncology*. 2004; 13(10):689–99.
8. Lee SJ, et al. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*. 2006; 24(18):2917–31.
9. Akabayashi A, Fetters MD, Elwyn TS. Family consent, communication, and advance directives for cancer disclosure: a Japanese case and discussion. *J Med Ethics*. 1999; 25(4):296–301.
10. Tang ST, et al. Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers in Taiwan. *Cancer Invest*. 2006; 24(4):360–6.
11. Thomasma D. Telling the truth to patients: a clinical ethics exploration. *Camb Q Health Ethics*. 1994; 3:375–82.
12. Mystakidou K, et al. Cancer information disclosure in different cultural contexts. *Support Care Cancer*. 2004; 12(3):147–54.
13. Feldman E. Medical ethics the Japanese way. *Hastings Cent Rep*. 1985; 15(5):21–4.
14. Nisker J, Baylis F, McLeod C. Choice in fertility preservation in girls and adolescent women with cancer. *Cancer*. 2006; 107(7 Suppl):1686–9.
15. Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. *N Engl J Med*. 2009; 360(9):902–11.
16. Wallace WH, Anderson RA, Irvine DS. Fertility preservation for young patients with cancer: who is at risk and what can be offered? *Lancet Oncol*. 2005; 6(4):209–18.
17. Wade N. Clinics hold more embryos than had been thought. *NY Times*. 2003; 9(24).
18. Ethics Committee of the American Society for Reproductive Medicine. Disposition of abandoned embryos. *Fertil Steril*. 2004; 82(Suppl 1):S253.
19. Strong C. The moral status of preembryos, embryos, fetuses, and infants. *J Med Philos*. 1997; 22:457–78.
20. Samuel S, Ed. *Consequentialism and its critics*. Oxford: Oxford University Press; 1988.
21. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. *Am J Prev Med*. 1999; 17(4):285–94.
22. Clayman ML, Galvin KM, Arntson P. Shared decision making: fertility and pediatric cancers. *Cancer Treat Res*. 2007; 138:149–60.