# Chapter 9
# Addressing the Three Most Frequently Asked Questions of a Bioethicist in an Oncofertility Setting

**Lisa Campo-Engelstein**

## Introduction

The goal of this chapter is to examine some of the ethical concerns that arise in the interdisciplinary field of oncofertility. Specifically, I will address what I have found—as a bioethicist within the Oncofertility Consortium [1]—to be the three most commonly asked ethical questions: (1) Who should be offered fertility preservation? (2) Who should pay for FP? and (3) How should disputes over frozen gametes, embryos, and gonadal tissue (collectively referred to as reproductive material) be resolved and prevented? Unfortunately, there are not always easy and universal answers to these questions. As with other aspects of patient care, we need to consider each patient and make a case-by-case judgment.

## Who Should Be Offered Fertility Preservation?

### *Age-Based Issues*

Offering medical treatment to minors raises a number of ethical concerns—too many to consider here—so instead, I will focus on the ethical concerns specific to fertility preservation. If a girl has reached puberty, then it is feasible for her to undergo controlled ovarian hyperstimulation with hormones to produce mature eggs

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L. Campo-Engelstein, Ph.D. (✉)
Alden March Bioethics Institute, Albany Medical College,
47 New Scotland Avenue, MC 153, Albany, NY 12208, USA
e-mail: campoel@mail.amc.edu

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or to create embryos for cryopreservation or “banking” (see Chap. 4 in this volume for a discussion of these options). However, some girls may not yet be emotionally mature to handle the medical procedure of egg removal. For example, the vaginal ultrasounds necessary to identify mature oocytes for retrieval may be traumatic to a girl who is not sexually active and/or has not yet had a gynecological visit. Furthermore, parents whose cultural and/or religious beliefs place a high value on a woman’s virginity may be concerned that their daughter will no longer be fully considered “pure” after such a procedure. If a girl and her parents want to use the most established form of fertility preservation for women—embryo banking—then she will have to choose a sperm donor, which is often difficult for adults to do, and so would probably be even more challenging for a teenager. In addition to emotional issues, there is also a concern about health risks, particularly those associated with ovarian hyperstimulation, in someone so young.

If a boy has reached puberty, then sperm banking is a relatively easy and established method of fertility preservation (see Chap. 3 in this volume for more information). Yet, some postpubertal boys may not have experience masturbating or have not been able to achieve orgasm. Discussing masturbation can be difficult and awkward, as most boys will probably be embarrassed, especially if their parents are present. Parents too can often feel embarrassed and may not be comfortable discussing their son’s sexuality. Depending on their cultural and religious beliefs, the parents may believe masturbation is a sin or that sexual behavior in teenagers and/or unmarried individuals should not be encouraged.

For prepubertal girls and boys, the only fertility preservation option available is gonadal tissue (or whole organ) banking (see Chap. 5 in this volume for further discussion). This option is considered experimental and thus should be discussed with caution and under IRB approval. Although surgical removal of the gonads is a low-risk procedure, some may be concerned about exposing children with cancer to yet another treatment, especially one that is experimental and addresses with a quality of life issue that probably will not affect the children for at least a decade.

In addition to concerns about offering fertility preservation to those on the younger end of age spectrum, there are also concerns about fertility preservation for those on the older end of the age spectrum. For most adult women, fertility begins to decrease in their 30s and significantly declines after age 37 [2, 3]. Some fertility clinics refuse to provide infertility treatment to women over 40 using their own eggs because the success rate is so low [4]. In order to maintain consistency and to avoid futile treatment, health-care providers should follow the guidelines set out by the American Society for Reproductive Medicine (ASRM) regarding age [3].

Since men do not experience the equivalent of menopause, they are able to reproduce throughout their lifetimes; however, studies have shown that the probability of infertility increases with age for men as well [2]. Additionally, the mere fact that they are able to reproduce does not mean that they should. Some have argued that there should be age restrictions not just for women but also for men when it comes to assisted reproductive technology due to concerns surrounding life expectancy, overall health, finances, etc. [5].

## *Prognosis*

Fertility preservation for patients with a poor prognosis raises a host of ethical issues. Providers may worry that discussing fertility preservation will give patients false hope about their prognosis. In other words, these patients may feel their providers deceived them by mentioning fertility preservation, leading them to believe that their prognosis is not as bad as they originally thought. Yet, at the same time, pursuing fertility preservation may be a source of hope and happiness for patients during difficult times. It may furnish them with mental and physical strength, making them even more motivated to survive for the sake of their potential future children. Additionally, these patients, and their families, may feel a degree of inner peace knowing that part of their lives will continue on in the reproductive material even if they are never used [6, 7].

Nevertheless, some may argue that, despite any personal and emotional benefits they may experience, offering patients with a poor prognosis fertility preservation options is an unjust allocation of resources. From a utilitarian perspective, it does not make sense to devote resources to patients who will likely not benefit from them. Put differently, resources should be allocated to those who have a high probability of a positive outcome, which means individuals with a poor prognosis should be placed lower on the priority list for receiving fertility preservation resources than individuals with a good prognosis.

On the other hand, if we take a deontological (duty-based, individual rights) approach, providers have a duty to care for their patients. Not offering fertility preservation to all of their patients, including those with a poor prognosis, may be seen as diminishing patient autonomy. According to this view, providers should be more concerned with the needs and rights of their individual patients than with social justice (i.e., fair allocation of resources).

## *Marital Status*

Some providers have been reluctant to treat unmarried individuals suffering from infertility [8]. Additionally, many insurance companies and state laws mandating insurance coverage of infertility treatment limit these services to married couples and, furthermore, require that only the gametes of the couple be used (i.e., donor gametes are prohibited) [9]. In the case of fertility preservation, denying patients this service does not make sense since most of them are minors and not legally permitted to be married or they are young adults who may see marriage as something they are not yet ready for but they would like in the future. Fertility preservation is inherently forward looking; that is, its purpose is to take the necessary precautions in order to ensure options (namely, biological parenthood) later on in life. Denying patients fertility preservation because they are unmarried at the time they seek treatment fails to recognize the future-oriented nature of fertility preservation treatment and that patients' marital status may change by the time they decide to use their reproductive material.

## Who Should Pay for Fertility Preservation?

As I have argued elsewhere, I believe insurance companies should cover fertility preservation for cancer patients [10, 11]. One of the strongest reasons is that insurance typically covers treatment for other iatrogenic conditions resulting from cancer treatment, including treatment that may otherwise be considered elective for conditions that “naturally” occur. For example, breast reconstructive surgery is covered by insurance when breast asymmetry (the extreme is the loss or lack of an entire breast) is iatrogenic but rarely when it is naturally occurring. The Women’s Health and Cancer Rights Act of 1998 institutionalizes the medical realm’s responsibility for iatrogenic harms by mandating that private health insurance companies cover the costs of breast reconstruction surgery if they cover the costs of mastectomy. As such, breast reconstruction surgery following mastectomy is coded as a cancer treatment rather than as an elective treatment. In contrast, it is highly unlikely that insurance companies will cover breast surgery to produce symmetrical breasts for a woman born with only one breast (an extremely remote or even unheard of phenomenon) or, as is more common, asymmetrical breasts.

The reason for this differential treatment can be partially explained by the harm principle and causal responsibility: if health-care professionals cause harm—a violation of Hippocratic Oath—then the medical profession as a whole must assume responsibility for alleviating this harm. Thus, if a woman has breast asymmetry or only one breast due to mastectomy (a medical procedure), the health insurance company should cover the expense of “fixing” her breast(s). Assuming there are no morally significant differences between breast surgery and fertility preservation—a claim I support in my previous works [10, 11]—insurance companies’ failure to cover fertility preservation is unjustified. In other words, for the sake of consistency and fairness, insurance companies should treat fertility preservation as a treatment for an iatrogenic condition (infertility) caused by cancer treatment.

Assuming insurance companies will not, or will only partially, pay for FP, how can health-care providers help individuals afford FP? One option is not to charge patients for the services received; however, this may not be within providers’ control, as hospitals and reproductive material storage facilities, for example, may still charge fees even if the provider does not. Furthermore, many of these services are quite expensive, and forgoing payment may be a financial hardship for providers. Another option is for providers to point their patients to external resources that provide financial assistance for fertility preservation procedures. The Lance Armstrong Foundation and Fertile Hope, for instance, offer aid to cancer patients who would like to pursue fertility preservation but are limited financially [12]. Providers can also refer their patients to institutions that offer discounted services, such as Northwestern University, which charges $5,000 for egg or ovarian tissue retrieval and freezing of eggs, embryos, or tissue [13]—a significant reduction from the average price of $12,513 for a cycle of in vitro fertilization (IVF) [14].

Even with financial assistance and a reduced price, the cost of fertility preservation procedures may still be prohibitive for some patients. Moreover, the cost of these procedures does not include storage fees and later use of reproductive material. Given that patients may have to undergo numerous attempts in order to achieve a pregnancy, it is not surprising that the average cost of a live birth baby using assisted reproductive technology is much higher than the average price for a cycle of IVF: $41,132 versus $12,513 [14]. Some providers may be concerned that discussing fertility preservation with patients who they know cannot afford it may be seen by their patients as cruel or callous.

Yet, there are several reasons why providers should always discuss fertility preservation, regardless of their patients' (presumed) financial circumstances. Providers are not privy to their patients' financial status, so determinations they make about whether patients can or cannot afford fertility preservation are, at best, estimated guesses. Even if patients disclose their financial circumstances to their providers, providers should not make value judgments regarding how patients should spend their money (e.g., spending funds on fertility preservation rather than a much-needed new car) as such judgments may preclude them from enumerating all of the patients' options. Additionally, providers may not be aware of external funds patients may receive from family members or others who have a stake in their health and the possibility of their future reproduction. That it may be difficult and upsetting for patients to learn about fertility preservation options even though they most likely cannot afford them should not affect the providers' decision to discuss those options. Giving bad news is an inherent aspect of the medical profession. While providers may struggle with sharing bad news with patients, it is essential that they do so in order to provide good care. Thus, in order to treat patients fairly and to provide the best care for all patients, providers should not let patients' finances determine what options are presented. To be clear, this does not mean that providers have to *perform* fertility preservation on their patients; I am merely claiming that providers should bring up fertility preservation as an option to all their patients rather than mentioning it selectively to those patients with higher socioeconomic status.

## How Should Disputes over Reproductive Material Be Resolved and Prevented?

Under the law, gametes and embryos are classified as a type of property, and people whose genetic material the gametes or embryos contain are the default owners of this property. As property, gametes and embryos can be bequeathed to others upon death just as one can bequeath a house or car. Unlike most other Western countries, the USA permits the sale of gametes. Given this legal understanding, disputes over reproductive material may have to be resolved in court if bioethics consultants or others cannot first help resolve the matter. Unfortunately, it is not possible to predict the outcome of these court cases because there is no set precedent in this matter and individual judges have ruled quite differently in similar cases [15–17].

The USA does not permit the same degree of commodification of organs as it does gametes and embryos. Organs are not viewed as property; thus, they cannot be bought and sold [18, 19]. However, donors can have some say in how their organs are allocated (e.g., a brother choosing to donate his kidney to his sister). Because gonadal tissue does not fit neatly into either of the two existing legal categories for body organs/cells/systems transplantation—organs or gametes/embryos—there is no legal precedent upon which to draw in disputes over ownership. As I have argued elsewhere, gonadal tissue should be legally classified similar to gametes/embryos because gonads are not currently regulated by the United Network for Organ Sharing and because gonads, unlike other organs but like gametes, can lead to pregnancy [19].

It is best to try to prevent disputes over reproductive material in the first place rather than deal with them after they have occurred. There are at least two ways to prevent such disputes. One way is to encourage individuals to freeze their gametes or gonadal tissue rather than creating and freezing embryos. Determining who should have control over reproductive material that contains just one person's genes is much easier than when reproductive material contains a mix of two people's genes. For men, this proposal is easy. Some women, however, may still prefer freezing embryos since freezing eggs, unlike freezing sperm, is still considered experimental and has a lower success rate than freezing embryos. Women in long-term, committed relationships are probably more likely to choose embryo freezing.

The easiest way to prevent disputes over any reproductive material is to have the patient write an advance directive that clearly outlines what should be done with the reproductive material should the patient die. If the reproductive materials are gametes or gonadal tissue, then ultimately, the decision of what to do with the reproductive material should be made by individual patients, as it is their genetic material. While patients may want to include their partner, family members, and friends in their decision making, health-care providers, patient navigators, and bioethicists should try to ensure that patients are indeed making their own decision and are not coerced by others when writing their advance directive.

## *Heterosexual Couples*

If the reproductive materials are frozen embryos, then it is important to look at who comprises the couple and whether each of them contributed genetic material. If the reproductive materials are embryos composed of both of a heterosexual couple's gametes, then patients and their partners should jointly make a decision and write an advance directive about reproductive material disposition together. As a way of avoiding future disputes, some clinics and providers refuse to treat couples if they cannot agree on future disposition of embryos. However, given the limited time frame in which fertility preservation must occur before cancer treatment can begin, refusing to treat an individual until they have agreed on these issues may prevent fertility preservation treatment altogether if the patient does not have the time or resources to seek treatment elsewhere.

For heterosexual couples where only the cancer patient contributes genetically to the embryos, prima facie, the case is much trickier than for couples who both contribute to the creation of the embryos. One could make the claim that these embryos should be treated like frozen gametes or gonadal tissue, meaning that the patient (who contributed genetically) should be the sole individual writing the advance directive. If the patient is male and his female partner is not able to contribute an egg, it would make more sense for him to freeze his sperm, as it is just as effective (if not more) and cheaper than embryo freezing. However, in the case of a female patient whose male partner does not contribute sperm, it becomes a bit more complicated because egg freezing is not as established as sperm freezing and is therefore not a simple alternative. The reason the male partner is not contributing (e.g., he is sterile vs. he does not want to create embryos with his female partner) should play a role in whether or how he should be involved in writing the advance directive. Ultimately, however, the female patient should make the decision about what role her partner will play in writing the advance directive.

## *Homosexual Couples*

Should cases of homosexual couples where only the cancer patient contributes genetically to the embryos be treated differently than cases of heterosexual couples where only the cancer patient contributes genetically to the embryos? This situation is more likely to affect lesbian couples than gay men since sperm freezing is easier, cheaper, and more established and successful than egg freezing. However, for both lesbians and gay men, partners who do not contribute genetically may still feel like they have a connection to the embryos because the couple intended to use the embryos to have children together and they would have contributed genetically if such technology existed. It makes sense to treat this case like the case of the female patient whose male partner is sterile and wants to contribute genetically but cannot due to biological factors beyond his control.

## *Minors*

Lastly, it is important to recognize the special category of minors to prevent disputes between children and their parents. Given that reproductive material is technically the property of the child, parents should not be allowed to use or discard their child's reproductive material before the child turns 18. Upon reaching legal adulthood, parents should relinquish all rights to the reproductive material, and it should be reclassified as the "property" of the child turned adult. If a minor child passes away, the child's reproductive material should be immediately destroyed or donated to science. Parents should not have the option of using their child's reproductive material for reproductive purposes. Indeed, posthumous reproduction by minor children should be prohibited.

## Conclusions

In this chapter, I have raised and addressed three of the most common ethical questions that oncofertility providers face, yet the practice of oncofertility clearly raises many additional ethical issues. Those working in the field of oncofertility, especially bioethicists, should strive not only to address these current ethical issues but also to predict future ethical issues and work to mitigate, prevent, or find solutions for them. It is also important for clinicians who care for cancer patients to understand the issues and anticipate these questions and work closely with bioethicists to address their patients' concerns about fertility preservation options.

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## References

1. Woodruff TK. The Oncofertility Consortium—addressing fertility in young people with cancer. Nat Rev Clin Oncol. 2010;7:466–75.
2. Dunson DB, Baird DD, Colombo B. Increased infertility with age in men and women. Obstet Gynecol. 2004;103:51–6.
3. Committee on Gynecologic Practice of American College of Obstetricians and Gynecologists; Practice Committee of American Society for Reproductive Medicine. Age-related fertility decline: a committee opinion. Fertil Steril. 2008;90:S154–5.
4. Garrido N, et al. Cumulative live-birth rates per total number of embryos needed to reach newborn in consecutive in vitro fertilization (IVF) cycles: a new approach to measuring the likelihood of IVF success. Fertil Steril. 2011;96:40–6.
5. Caplan AL, Patrizio P. Are you ever too old to have a baby? The ethical challenges of older women using infertility services. Semin Reprod Med. 2010;28:281–6.
6. Maltaris T, et al. Reproduction beyond cancer: a message of hope for young women. Gynecol Oncol. 2006;103:1109–21.
7. Quinn GP, et al. Frozen hope: fertility preservation for women with cancer. J Midwifery Womens Health. 2010;55:175–80.
8. Robinson BE. Birds do it. Bees do it. So why not single women and lesbians? Bioethics. 1997;11:217–27.
9. Basco D, Campo-Engelstein L, Rodriguez S. Insuring against infertility: expanding state infertility mandates to include fertility preservation technology for cancer patients. J Law Med Ethics. 2010;38:832–9.
10. Campo-Engelstein L. Consistency in insurance coverage for iatrogenic conditions resulting from cancer treatment including fertility preservation. J Clin Oncol. 2010;28:1284–6.
11. Campo-Engelstein L. For the sake of consistency and fairness: why insurance companies should cover fertility preservation treatment for iatrogenic infertility. Cancer Treat Res. 2010;156:381–8.
12. Fertile Hope. Financial assistance. 2011. http://www.fertilehope.org/financial-assistance/index.cfm. Accessed 2 Aug 2011.
13. Smith K. Cost of fertility preservation treatment at Northwestern University, Campo-Engelstein L, editor. 2011 (Personal communication).
14. Chambers GM, et al. The economic impact of assisted reproductive technology: a review of selected developed countries. Fertil Steril. 2009;91:2281–94.

15. Elster NR. Assisted reproductive technologies: contracts, consents, and controversies. Am J Fam Law. 2005;18:193–9.
16. Kingdregan CP, Snyder SH. Clarifying the law of ART: the new American Bar Association model act governing assisted reproductive technology. Fam Law Q. 2008;42:203–29.
17. Fuselier BM. The trouble with putting all of your eggs in one basket: using a property rights model to resolve disputes over cryopreserved pre-embryos. Texas J Civil Lib Civil Rights. 2009;14:143–91.
18. National Organ Transplantation Act, 42 USC §273 (1984).
19. Campo-Engelstein L. Gametes or organs? How should we legally classify ovaries used for transplantation in the USA? J Med Ethics. 2011;37:166–70.