

Consistency in Insurance Coverage for Iatrogenic Conditions Resulting From Cancer Treatment Including Fertility Preservation

Lisa Campo-Engelstein, *Oncofertility Consortium, Northwestern University, Chicago, IL*

INTRODUCTION

Insurance companies generally cover treatment for iatrogenic conditions that result from cancer treatment, including treatment for conditions that may be considered elective when “naturally” occurring (note that in this article, I am using the word “iatrogenic” to refer only to nonnegligent treatment-induced conditions). One notable exception is fertility preservation for iatrogenic infertility. In this brief article, I argue that for insurance companies to maintain consistency, they should cover fertility preservation treatment for female patients with cancer because it does not differ significantly from other treatments for iatrogenic conditions they currently cover for women, such as breast reconstruction after mastectomy and wigs for alopecia. (Although my focus in this article is on female fertility preservation, one could presumably make a similar argument that male fertility preservation should be covered by insurance.)

One reason many insurance companies refuse to cover fertility preservation treatments, and infertility treatments more generally, is that they are often viewed as elective procedures, not medically necessary ones. When it comes to iatrogenic infertility, however, the controversy over whether fertility preservation is a medically necessary treatment should be moot because other so-called elective procedures are covered when they are iatrogenic, even if they are not covered when naturally occurring. Because my focus is on iatrogenic conditions—many of which, as I will discuss in this article, are generally not considered medical conditions when they are not iatrogenic—I put aside the debate about whether infertility should be classified as a “real” disease. One example of an iatrogenic condition typically covered by insurance is breast reconstruction after lumpectomy or mastectomy. Although having only one breast is rarely, and perhaps never, a naturally occurring condition, naturally occurring breast asymmetry is quite common. Most would not classify breast asymmetry as a medical problem that insurance should cover. However, when breast asymmetry results from a lumpectomy, surgery to achieve symmetry is usually covered regardless of whether the patient had symmetric breasts beforehand. This discrepancy in coverage between iatrogenic and naturally occurring breast asymmetry can be explained, at least in part, by looking at the harm principle through the lens of responsibility: because members of the medical profession caused the harm—something they are not supposed to do—the medical profession as a whole must take responsibility for mitigating the

harm. (Another factor is the static understanding of the body that dominates medicine and science. Briefly, this is the idea that the body stays the same over time and disease is aberration that must be eradicated to restore the body to its natural and “normal” state. See Eckenwiler¹ for a discussion of how this static understanding of the body has led to women’s exclusion from clinical research trials.)

Certain acts and laws were passed to institutionalize the medical realm’s responsibility for iatrogenic harms. For instance, the Women’s Health and Cancer Rights Act, which was passed in 1998, mandates that if health insurance companies cover the costs of mastectomy for cancer patients, then they must also cover the costs of breast reconstruction for mastectomy patients.² Health care providers and insurance companies sometimes assume responsibility for iatrogenic harms by the way they code for billing. For example, breast reconstruction surgery after a mastectomy is coded as cancer treatment rather than under elective treatment. By allowing treatments for iatrogenic conditions to be subsumed into the larger category of disease treatment, insurance companies are tacitly accepting financial responsibility to cover these treatments. In addition to breast reconstruction surgery, there are other treatments that may not be covered by insurance when the disease is naturally occurring (in part because treatment is not seen as medically necessary), but are covered when iatrogenic; for example, wigs after cancer treatment are usually covered, whereas wigs for thinning hair or cosmetic reasons often are not.

The same pattern of insurance coverage exists in the fertility/infertility realm. Many insurance companies do not cover infertility or fertility preservation treatments for some of the following reasons: in/fertility treatments are experimental, they do not treat an underlying disease but rather produce a desired outcome (ie, a child), and they are an elective procedure, not a medical one.³ An exception to the lack of coverage is iatrogenic infertility. Although no formal studies have been done, there is anecdotal evidence that insurance companies will sometimes take financial responsibility for iatrogenic infertility. At the Northwestern University branch of the Oncofertility Consortium (www.oncofertility.northwestern.edu), a national, interdisciplinary initiative designed to explore the reproductive options for patients diagnosed with cancer or other serious diseases, female patients with cancer have the option to choose a fertility preservation method—embryo, egg, or ovarian tissue cryopreservation—before beginning cancer treatment. These fertility preservation treatments have been billed under a primary diagnosis of cancer and a secondary diagnosis

of procreative management. Although there have been many appeals and much negotiation, so far insurance companies have covered this treatment for all of the patients (M. Gerrity, personal communication, June 2009). Fertile Hope, a nonprofit organization that provides reproductive information and support to patients with cancer and survivors, also notes that some patients with cancer have been able to convince their insurance companies to cover fertility preservation by claiming that insurance companies cover side effects of all other medically necessary cancer treatment and that infertility should not be different.⁴

Some may argue that insurance companies should not cover these fertility preservation methods for patients with cancer because this treatment differs in significant ways from treatment for other iatrogenic conditions. I will explore and respond to five objections.

First, egg and ovarian tissue cryopreservation are considered experimental procedures and insurance companies rarely, and perhaps should not, cover experimental procedures. Although it is true that the American Society for Reproductive Medicine still defines egg cryopreservation as experimental,⁵ this technology, especially egg freezing using vitrification, is improving rapidly, and some in the scientific community no longer view it as experimental.⁶ Additionally, egg and ovarian tissue cryopreservation are the only available options for young and/or single women to be able to have a child with a future partner, not a sperm donor. Creating embryos, the only mature technology, run the risk that the biologic father could oppose transfer. As a matter of social justice, we need to have fertility preservation options available to women independent of men to ensure that a woman will be able to have a biologic child and with the man she chooses.

Second, patients with cancer do not meet the definition of infertility. When insurance companies do cover infertility treatment, it generally only applies to those diagnosed as infertile, which usually is defined as the inability to conceive after 1 year of regular and unprotected heterosexual intercourse. Although patients with cancer are not technically infertile at the time when fertility preservation treatment would take place (right before the commencement of cancer treatment), for many, infertility is an unfortunate inevitability. Although it is difficult to precisely predict one's chance of infertility, some treatments generally yield infertility rates of 80% or more. Indeed, some estimate that up to 90% of patients with cancer in their reproductive years will be rendered infertile from treatment.⁷ Although it is true that patients with cancer do not fit the standard definition of infertility, this does not mean that their need for infertility treatment is any less. In fact, in some ways, their need for infertility treatment is greater. Unlike traditional infertility patients who can continue receiving infertility treatment until they conceive, patients with cancer often only have one shot at preserving their fertility as it must occur before they begin cancer treatment. The unique situation that patients with cancer face reveals the traditional definition of infertility as too limited, for it cannot account for fertility preservation needs of those with foreseeable iatrogenic infertility.

Third, insurance companies tend to cover iatrogenic conditions that already exist, like hair loss from chemotherapy, or will almost certainly exist, like loss of an entire breast after mastectomy, not conditions that may (or may not) exist in the future, like infertility. However, a low probability of occurrence should not lead providers to forgo prophylactic procedures to avoid iatrogenic conditions. And, in fact, providers typically provide treatments to prevent iatrogenic conditions that may (or may not) occur, such as antiemetics for nausea

and dental evaluations for osteoradionecrosis. Another example that is more analogous with fertility preservation that providers sometimes recommend is storing one's own blood as a prophylactic precaution in case of an emergency transfusion. Those who seek fertility preservation treatment are similarly motivated as those who store blood: in a worst-case scenario—patients find themselves infertile after cancer treatment—these patients have a reserve of gametes to use to have biologic children.

Although treatment for most iatrogenic conditions generally occurs very soon or immediately after cancer treatment, in the case of fertility preservation, frozen embryos, eggs, and ovarian tissue may not be used for many years, even decades. However, according to the principle of moral neutrality, the timing of a harm has no moral significance.⁸ Consequently, the time at which a woman experiences the harm of iatrogenic infertility—whether it is 6 months or 6 years after treatment—does not change the degree of harm.

Fourth, when insurance companies cover iatrogenic conditions that would not be covered when naturally occurring (eg, breast surgery and wigs), part of the reason for doing so is because the results of the treatment, which is visible to both the patient and others, normalizes the patient's gendered body and identity. Women without certain gender markers, like breasts or head hair, often feel less feminine, which affects their sense of self and quality of life. Moreover, others in society may feel uncomfortable with and act differently toward a woman whose physical appearance does not match the "normal" female body. Yet, fertility preservation treatment also normalizes women's gendered body and identity in a visible way. In addition to the fact that motherhood is an important part of many women's identity, there is a social expectation that women have children. Pregnancy is one of the most visible symbols of femininity, as is a woman caring for children.

Fifth, fertility preservation treatment is inherently more socially and ethically complex because it not only affects the individual patient, but it also involves and impacts her current or future partner, as well as her family (eg, her parents, children, and so on) and future offspring, in ways that treatment for other iatrogenic conditions does not. Although fertility preservation treatment is indeed more socially and ethically complex, I do not think this difference is pertinent to discussions of insurance coverage. Insurance companies often cover socially and ethically complex procedures outside of assisted reproductive technology (ART), including corrective surgery for intersex infants, fetal surgery, and genetic testing for hereditary diseases. The social and ethical complexity of the treatment should not factor into coverage decisions, though it may be an indicator that patients need extra counseling before making treatment decisions.

In short, fertility preservation treatment for patients with cancer does not differ in morally significant ways from treatments for other iatrogenic conditions that are currently covered by insurance and thus its exclusion from insurance coverage is unjustified. As the field of oncofertility continues to develop and fertility preservation options continue to progress, insurance companies will increasingly be confronted with how to handle iatrogenic infertility for patients with cancer. I have argued that insurance companies should, for the sake of consistency, cover fertility preservation treatment for patients with cancer. Given the controversy surrounding reproductive technologies, this suggestion may be met with fierce opposition. However, it is time for insurance companies to stop relegating reproductive technologies to a separate realm outside of "real" healthcare, especially when

they cover treatment for conditions that are similar to infertility. The fact that insurance companies have begun covering fertility preservation treatment for patients with cancer gives hope that fertility and infertility treatment is finally being taken seriously by insurance companies. Yet this coverage is done secretly on a case-by-case basis rather than with a blanket policy, which implies that insurance companies are still not ready to publicly assume financial responsibility for iatrogenic infertility (M. Gerrity, personal communication, June 2009).

Perhaps a state or federal mandate, modeled after the Women's Health and Cancer Rights Act, is necessary for insurance companies to begin openly and universally covering treatment for iatrogenic infertility. On the patient level, a mandate would open the door for more discussions between patients and providers about fertility preservation treatment. According to recent studies, more than half of female and male patients with cancer of reproductive age have no memory of discussing fertility during their initial oncology appointments. For those patients who did have such discussions, many were dissatisfied with both the quality and the amount of information provided. Educating providers about ART is key to engendering fertility discussions. However, it may not be enough. Some providers do not discuss infertility because they believe their patients will not be able to afford ART.⁶ A mandate for coverage of iatrogenic infertility would alleviate this concern, thereby propelling providers to talk about ART with patients of all socioeconomic statuses. Indeed, a mandate would provide greater ART access to patients from lower socioeconomic backgrounds, to patients without insurance, and/or to patients who do not have patient advocates to help them secure funding for this technology.

On the broader social level, a mandate would symbolize recognition of the importance of fertility for patients with cancer; it would acknowledge that fertility preservation, just like breast reconstruction

after mastectomy, is a significant quality-of-life issue for patients with cancer. Moreover, such a mandate would move away from many insurance companies' classification of ART as so-called boutique medicine rather than understanding infertility as a serious disease worthy of medical treatment. Although there is a growing consensus among health organizations (including the US Centers for Disease Control and Prevention and the WHO) and medical professionals that infertility is a disease as well as a public health matter, many insurance companies treat ART like they fall outside the scope of real medicine. Currently, 14 states have some type of ART mandate. State mandates specifically for iatrogenic infertility could serve as a stepping stone toward state mandates for infertility more generally.

AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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