

Chapter 29

For the Sake of Consistency and Fairness: Why Insurance Companies Should Cover Fertility Preservation Treatment for Iatrogenic Infertility

Lisa Campo-Engelstein

L. Campo-Engelstein (B) Oncofertility Consortium and Center for Bioethics, Science & Society, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA e-mail: ltce@northwestern.edu

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There is much debate not only about the morality of assisted reproductive technologies (ART) but also about how they should be classified. Should ART be understood as medical treatment for a disease (infertility) or should they be relegated to boutique medicine where they are seen as elective? How we answer this question affects our thoughts about whether ART should be covered by insurance companies. Those who claim infertility is a medical disease usually advocate that ART be covered by insurance. Conversely, those who believe ART are elective procedures generally oppose insurance coverage, insisting that insurance coverage should be limited to medically necessary treatments. While the debate cannot simply be reduced to whether “real” diseases should be covered by insurance and all other conditions should not, in the minds of many, a strong connection exists between what is considered a disease and what insurance should cover. For the purposes of this chapter, therefore, the belief that medically necessary conditions should be covered by insurance whereas elective conditions should not will serve as the basis of the discussion.

Most discussions of ART focus on their use in two circumstances: first, to treat people currently suffering from infertility due to disease (e.g., endometriosis) or unknown cause, and second, and more recently, to provide “insurance” against age-related infertility for women who plan to delay childbearing. Though still a contentious issue, the former – disease-induced infertility – is typically thought to be more deserving of insurance coverage than the latter – age-related infertility – because the cause of infertility is a disease, a “legitimate” medical problem rather than an individual’s action. Indeed, some have argued that insurance should cover treatment for the underlying disease that is causing infertility (e.g., open a blocked fallopian tube) even if they do not think they should cover ART (Gerrity, 2009, Executive Director of the Oncofertility Consortium, Personal conversation). The perceived cause of age-related infertility is, in contrast, not often seen as legitimate but rather as the result of individual women’s bad choices and selfishness. According to this view, women’s desire to have a career leads them to delay childbearing, which is no one’s fault but of their own (Goold and Savulescu discuss, and argue against, this position) [1]. In short, age-related infertility is not a medical problem and thus should not be covered by insurance.

Although my discussion in this chapter centers on infertility and insurance coverage, it diverges from these other debates in two significant ways. First, I will bypass the

question of whether infertility should be classified as a disease. Second, I do not deal with disease-induced or age-related infertility; rather, I focus on another circumstance in which one might use ART: before undergoing necessary medical treatment that may lead to infertility. Specifically, I am concerned with fertility preservation procedures for cancer patients about to receive chemotherapy and/or radiation, both of which often cause infertility. I will refer to this type of infertility as iatrogenic infertility.

An iatrogenic condition is a negative side effect or adverse condition that is caused by the diagnosis, manner, activity, or treatment of a health-care provider. I recognize that this is a loaded term (which insurance companies and providers typically do not like to use), in part because some see it as a normative term implying providers' wrongdoing and blame. While this term encompasses negligent iatrogenic conditions, such as a surgeon leaving a scalpel inside the body of a patient, in this chapter I am using it to refer only to non-negligent conditions. Non-negligent iatrogenic conditions occur when medically necessary treatments have unavoidable and/or unpredictable negative side effects, such as cancer treatment causing infertility, hair loss, or nausea. Providers are not to blame in these situations, as they face a no-win situation: in order to treat and hopefully save their patients' lives, they must also harm them. Unfortunately, the nature of certain cancer treatments, as well as various treatments for other diseases, is inherently harmful (e.g., destroying healthy cells along with cancerous ones).

Insurance companies generally cover treatment for iatrogenic conditions that result from cancer treatment, even though they do not cover these same conditions when they are "naturally" occurring. Infertility treatment, on the other hand, is typically not covered, regardless of whether it is iatrogenic or naturally occurring. One reason many insurance companies refuse to cover ART is that they are often viewed as elective procedures, not medically necessary ones. However, based on insurance coverage patterns for other "elective" procedures performed in response to iatrogenic conditions, insurance companies should also cover ART, specifically fertility preservation treatment (i.e., cryopreservation of eggs, embryos, or ovarian tissue for later use), for female cancer patients. In this way, insurance companies will maintain consistency and promote fairness, since fertility preservation does not differ significantly from other treatments for iatrogenic conditions they already cover for women. While my focus is on female fertility preservation, one could presumably make a similar argument that male fertility preservation should be covered by insurance.

In order to support this claim, I compare ART for iatrogenic infertility to breast reconstruction surgery following lumpectomy or mastectomy, which is generally covered by insurance. I choose this comparison because just as in the case of infertility, there is probably not agreement on whether breast construction surgery for women who naturally have only one breast is medically necessary or elective. While I recognize that having only one breast is rarely, and perhaps never, a naturally occurring condition, this comparison makes for a good thought experiment. I will briefly explore the different ways of understanding and classifying this condition to highlight the discord.

Most would agree missing a breast is not a life-threatening situation. However, it would probably adversely affect a woman's quality of life. For example, surveys have shown that the loss of a breast makes women feel like less feminine – that is, less of a “real” woman – and I imagine women born without a breast would have similar emotions [2, p. 164]. Moreover, women without two breasts may also make others feel uncomfortable because these women do not have all the typical feminine gender markers (e.g., gender markers include breasts, hips, long(er) hair, and lack of facial hair). Indeed, the social response to women with one or no breasts may mimic the social response to people who are intersex, as their physical appearance does not match the “normal” female or male body. Yet, some have argued that the condition of intersex is largely a social, not medical, problem as it generally does not cause any physical health problems and instead causes strong cultural discomfort by blurring and confusing the gender lines (see Alice Dourmat Dreger, for example) [3]. Likewise, one could claim having only one breast does not lead to physical health problems, only personal and cultural angst, so it should not be understood as a disease in need of surgery. Those who support a narrow, scientific definition of disease based on biological functioning may agree that having only one breast does not require treatment and may assert that this condition is just an anomaly like six fingers. Constructionist perspectives on disease echo this belief, insisting that not all anomalies are diseases: “to call something a disease involves both a claim about the abnormal functioning of some bodily system and a judgment that the resulting abnormality is a bad one” [4, p. 3]. According to this view, classifying a condition as a disease is a normative claim, so determining whether having one breast is a medical condition involves drawing on one's own subjective values and judgments. Some may concur that having one breast engenders social problems, not physical health problems, yet still view this condition as a disease in need of treatment. This claim relies on a broad definition of health, like the one used by the World Health Organization: “health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” [5]. Under such a definition, having only one breast would be considered a condition that interferes with one's social and mental health and quality of life. Consequently, it should receive treatment.

The above discussion shows that there is probably not much consensus on whether surgery for women who naturally have only one breast is medically necessary or elective. The same is true for ART to treat infertility: there is little agreement on whether these procedures are medically necessary or elective. This similarity is important because while breast surgery is covered by insurance when iatrogenic, probably not all insurance companies would cover this surgery when it is naturally occurring. As such, even though ART are often not covered due to differences in how infertility is understood and classified, insurance companies should cover ART in cases of iatrogenic infertility because it promotes consistency and fairness.

However, the case for insurance coverage for iatrogenic infertility using the above comparison may remain unconvincing due to the small prevalence of women with only one breast. A more common condition for which there would probably be greater consensus about its treatment as elective is asymmetrical breasts. While having only one breast is rarely, and perhaps never, a naturally occurring condition, naturally occurring

breast asymmetry is quite common. Insurance companies rarely cover surgery for naturally occurring asymmetrical breasts and I imagine most people would agree with this decision. Breast asymmetry is rarely as conspicuous or socially isolating as having only one breast, so it makes sense that it would rank lower on the list of conditions that should be covered by insurance. Indeed, surgery to “remedy” breast asymmetry is often put on par with other “purely” cosmetic procedures, such as otoplasty for “protruding” ears and rhinoplasty for “overly large” or “overly wide” noses. In sum, while these procedures can improve individual self-esteem and thus quality of life, they are not generally seen as anything other than elective.

While surgery for naturally occurring breast asymmetry is usually considered elective and thus not generally covered by insurance companies, surgery to resolve breast asymmetry that results from a lumpectomy is usually covered, implying that the procedure is medically necessary. Moreover, in the case of iatrogenic breast asymmetry, this surgery is covered regardless of whether the patient had symmetrical breasts beforehand. Likewise, breast reconstruction surgery following mastectomy is typically covered, despite the debate over whether breast construction surgery should be covered for naturally occurring “missing” breasts. This discrepancy in breast surgery coverage between iatrogenic and naturally occurring conditions can be explained, at least in part, by looking at causality. According to one view, iatrogenic conditions are caused by the medical realm and therefore the medical realm – specifically the insurance companies – should take financial responsibility. In other words, 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. The same principles apply when naturally occurring conditions are thought to be caused by bad luck or, at times, by the individual herself. Since the medical realm is not causally responsible for these naturally occurring conditions, one could argue that they should not be financially responsible for them. At play in this connection between causality and responsibility 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. If any alterations occur in the process of healing the body, health-care providers should do their best to fix them so that the person’s body is as close as possible to her original state when they are finished.

Certain acts and laws were passed in order to institutionalize the medical realm’s responsibility for iatrogenic harms. For instance, the Women’s Health and Cancer Rights Act, 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 those patients [6]. Health-care providers and insurance companies sometimes assume responsibility for iatrogenic harms by the way they code for billing. For example, breast reconstruction surgery following a mastectomy is coded as cancer treatment rather than 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 following cancer treatment are usually covered, whereas wigs for thinning hair or “cosmetic” reasons often are not.

The same pattern of insurance coverage seems to exist, though more covertly, in the fertility/infertility realm. Although 14 states now have laws mandating insurance companies to cover infertility treatment under certain circumstances [7], many insurance companies refuse to cover naturally occurring infertility or fertility preservation treatments. Reasons that insurance companies give for why ART should not be covered include the following: in/fertility treatments are experimental, they do not treat an underlying disease but rather produce a desired outcome (i.e., a child), and they are an elective procedure not a medical one [8]. However, there is growing evidence that insurance companies are covering iatrogenic infertility resulting from cancer treatment. Although no formal studies have been done, anecdotal data demonstrate that insurance companies will sometimes take financial responsibility for iatrogenic infertility. At the Oncofertility Consortium, female cancer patients 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 Consortium’s patients (Gerrity, 2009, Executive Director of the Oncofertility Consortium, Personal conversation). Fertile Hope, a nonprofit organization that provides reproductive information and support to cancer patients and survivors, also notes that some cancer patients have convinced 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 [9].

The trend toward covering ART for cancer patients with iatrogenic infertility is a move in the right direction, as it creates consistency in coverage policy instead of treating in/fertility differently than other iatrogenic conditions. However, some may argue that insurance companies should not cover these treatments because they differ in significant ways from treatments for other iatrogenic conditions.

One objection to insurance coverage for iatrogenic infertility treatment may be that some ART, in particular egg and ovarian tissue cryopreservation, are considered experimental procedures, whereas breast reconstruction surgery is an established procedure. By practice, insurance companies rarely cover experimental procedures. Although the American Society for Reproductive Medicine still defines egg cryopreservation as experimental [7], this technology, especially egg freezing using vitrification, is improving rapidly and some in the scientific community no longer view it as experimental [10]. 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 biological father could oppose transfer. As a matter of social justice, fertility

preservation options that do not require sperm need to be available to women in order to ensure they will be able to have a biological child and with the man they choose.

A second objection is that insurance companies tend to cover iatrogenic conditions that currently exist, like hair loss from chemotherapy, or that will almost certainly exist, like loss of an entire breast following mastectomy, not conditions that may or may not exist in the future, like infertility. Yet, a low probability of occurrence should not lead providers to forgo prophylactic procedures to avoid iatrogenic conditions. 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. Health-care providers also often recommend storing one's own blood as a prophylactic precaution in the case of an emergency transfusion. Whether the stored blood will be used cannot be predicted, but patients often want to be prepared for the worse case scenario. Those who seek fertility preservation treatment are similarly motivated as those who store blood: in a worse case scenario – where patients find themselves infertile after cancer treatment – these patients have a reserve of gametes to use to have biological children.

While treatment for most iatrogenic conditions generally occurs very soon or immediately after cancer treatment, in the case of fertility preservation, frozen embryos, eggs, 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 [11]. Consequently, the time at which a woman experiences the harm of iatrogenic infertility – whether it is 6 months or 6 years following treatment – does not change the degree of harm.

A third objection is that when insurance companies cover iatrogenic conditions that would not be covered when naturally occurring (e.g., breast surgery and wigs), part of the reason for doing so is that the results of the treatment, which are 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.

A fourth objection to insurance coverage is that fertility preservation treatment is inherently more socially and ethically complex because it not only affects the individual patient but also involves and impacts her current or future partner, her family (e.g., her parents, children), and future offspring in ways that treatment for other iatrogenic conditions does not. While fertility preservation treatment is indeed more socially and ethically complex than other treatments, this difference is not pertinent to discussions of insurance coverage. Insurance companies often cover socially and ethically complex procedures outside of 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.

Unlike the first four objections, the last objection does not compare ART with other treatments that are covered. Rather, it deals with the appropriateness of providing ART to cancer patients because cancer patients do not meet the definition of infertility. When insurance companies do cover infertility treatment, it generally only applies to those diagnosed as infertile, commonly defined as the inability to conceive after 1 year of regular and unprotected heterosexual intercourse. Although cancer patients are not 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 following some treatments. While it is difficult to precisely predict a patient's chance of infertility, some treatments generally yield infertility rates of 80% or more [12]. Although it is true that cancer patients do not fit the standard definition of infertility, this does not mean that their need for infertility treatment is any less – in some ways, their need for infertility treatment is greater. Unlike traditional infertility patients who can continue receiving infertility treatment until they conceive, cancer patients often only have one opportunity at preserving their fertility as it must occur before they begin cancer treatment. The unique situation cancer patients face reveals the traditional definition of infertility as too limited, for it cannot account for the fertility preservation needs of those with foreseeable iatrogenic infertility.

As the field of oncofertility continues to develop and fertility preservation options continue to expand, insurance companies will increasingly be confronted with how to handle iatrogenic infertility for cancer patients. I have argued that ART for cancer patients are similar to treatments for other iatrogenic conditions that are currently covered by insurance and thus their exclusion from insurance coverage is unjustified. Insurance companies should, for the sake of consistency and fairness, cover fertility preservation treatment for cancer patients. Given the controversy surrounding reproductive technologies, this suggestion may be met with fierce opposition. However, it is time for insurance companies to stop relegating ART to a separate realm outside of “real” health care, especially when they cover treatment for conditions that could also be perceived as elective. The fact that insurance companies have begun covering fertility preservation treatment for cancer patients gives hope that fertility and infertility treatments are finally being taken seriously by insurance companies. Nevertheless, this coverage is done covertly on a case by case basis rather than under a blanket policy, which insinuates that insurance companies are still not ready to publicly assume financial responsibility for iatrogenic infertility (Gerrity, 2009, Executive Director of the Oncofertility Consortium, Personal conversation).

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. Such a mandate would not only symbolize the importance of fertility preservation treatment and the severity of infertility as a disease but also open the door for more discussions between patients and providers about fertility

preservation treatment. Furthermore, a mandate would provide greater access to patients from lower socioeconomic statuses, to patients without insurance, and/or to patients who do not have patient advocates to help them secure funding for this technology.

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