

## Chapter 14

### Morally Justifying Oncofertility Research

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#### Introduction

Is research aimed at preserving the fertility of cancer patients morally justified? In response to this question, some people would resoundingly answer “yes.” Many oncofertility researchers and some survivors of cancer who are now infertile would probably react this way. But others might say “no,” in particular people who worry about the just distribution of scarce resources, the risks to patients and to their potential offspring of the relevant interventions [1], or pronatalist and other biases that seem to underlie this science. While I lean toward “no” myself, I recognize that the issue is complicated. I also believe that it must be confronted. Some people will try to dodge the issue by presuming that oncofertility research is justified, on the grounds that it promotes a basic right (to reproduce) or resembles research that our society has already condoned (i.e., research into other assisted reproductive technologies (ART)). But actually, there is no getting around the need to justify this research and to do so on moral as well as legal grounds. My concern specifically is with its *moral* justification.

In my view, a sound moral justification for oncofertility research is missing from the literature on oncofertility. Rather than fill this gap myself – which I think is impossible to do in a short space and which is also a job for an advocate, not a skeptic, of the science – my goal in what follows is to explain what I think such an argument must look like.

#### Why Do the Research?

Moral justifications for oncofertility research often refer, understandably, to the suffering that cancer survivors experience if they are infertile because of their cancer treatments. Reproductive autonomy is relevant here, even though the focus is on suffering, not autonomy. The idea is that the potential for future suffering justifies giving cancer survivors the choice of whether to preserve their fertility and use the preserved gametes or tissue in the future to attempt to have their own genetically related children. I will give a representative example of such an argument, analyze it, and explain why it and arguments like it are flawed.<sup>1</sup>

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<sup>1</sup> I do not look at reproductive rights arguments in favor of oncofertility research. I know of one such argument: that of Leilah Backhus and Laurie Zoloth in the last oncofertility volume [3]. According to Backhus and Zoloth, oncofertility research will protect people’s right to reproduce, which they describe as

The representative example comes from Philip Rosoff and Melanie Katsur [2]. The following is the positive argument they give for pursuing oncofertility research:<sup>2</sup>

- P1) A common complication of cancer treatment is infertility.
- P2) Infertility “can be [and often is] a devastating experience, especially for women” [3].
- P3) Available data on cancer survivors and the clinical experience of one author suggest that cancer survivors are no different than the rest of us: many want genetically-related children<sup>3</sup> and infertility is or can be devastating for many of them, especially the women.
- P4) Genetic parenting is “one of life’s greatest fulfillments” [4].
- C) Thus, providing cancer patients, especially female patients, with the chance of preserving their fertility is worthwhile, and this in itself justifies the research.

The overall concern here is with the happiness or life satisfaction of cancer survivors. The thought is that having genetic children will add significantly, and may in fact be essential, to their well-being. I take it that if asked whether oncofertility research is justified, many people would give a response similar to Rosoff’s and Katsur’s. But is their argument compelling? We should ask two things about it: first, are its premises all true? Second, does its conclusion follow logically from its premises? Beginning with the first question, I assume that we can accept P1, but what about P2–P4? What evidence do Rosoff and Katsur provide for their truth and is that evidence sufficient?

The first of these premises, P2, has to do with how infertility impacts on people’s lives. Many of us believe that infertility is or at least can be devastating, especially for women. Our grounds for this belief may be that people in general, but women in particular, have strong reproductive instincts that when thwarted cause them great suffering. Rosoff and Katsur make such a claim, and also bolster their argument with an appeal to psychological literature about the psychological distress that often accompanies infertility.

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an “important freedom within society that is seldom questioned or restricted” (166). They give a significant amount of weight to this freedom, which they justify by appealing to the work of John Robertson [4], but also by claiming that infertility is a disease or disability that people ought to have the freedom to overcome. I am doubtful that Backhus and Zoloth do enough to show that a right to reproduce justifies this research (especially if the right is negative, which is how a right to reproduce is normally understood, and if the science is publicly funded). But I do not engage with their argument here and thus do not show definitively that compelling arguments in favor of oncofertility science are absent from the literature.

<sup>2</sup> I have omitted their responses to reasons others might give for not doing this research; e.g., that patients could not meaningfully consent to it or that potential harms to offspring would be too great (16).

<sup>3</sup> Rosoff and Katsur use the expression “biologic children” but I prefer instead “genetically-related” or “genetic children.” In my view, the category of biologic children is larger than that of genetic children. Children to whom women give birth but to which they are not genetically related are still the women’s biologic children because of a biological tie created during pregnancy. Fertility preservation can allow oncofertility patients to have genetic children, but may not be necessary for them (particularly for the female patients) to have biologic children.

Let me comment first on the appeal to reproductive instinct. Insofar as we have such a drive, is it “rooted in biology” or in social conditioning [5]? Rosoff and Katsur’s answer seems to be “both” [2]. But of course it is hard to know whether or how much biology plays a role here because society weighs in so heavily in favor of many of us having biologic children [6].<sup>4</sup> Social influences alone could explain why many people yearn for biologic children, why many view adoption as a last resort, and why many regard childlessness as a fate almost worse than death. Rosoff and Katsur suggest that the eventual frustration of a strong urge to procreate warrants a medical response: that of fertility preservation. Many people would oppose this move however if the procreative desire were entirely the product of socialization, although the move is questionable even with desires that are purely biological. One cannot justify a medical intervention simply by showing that it would prevent a strong desire from being frustrated, regardless of the origins of the desire and regardless of whether the person would be devastated if the desire were not satisfied. For example, risky and invasive cosmetic surgeries may not be justified even if women desire them intensely because they have been socialized to find their aging bodies disgusting. The same is true of extraordinary measures to keep dying children alive for which parents beg because of a powerful instinct to want their children alive. In short, claims about instinct may not show very much.

Nevertheless, that infertility prevents the satisfaction of a strong desire and thereby causes feelings of devastation could contribute to the justification of fertility preservation. But do we know that infertility has this effect? What proof do Rosoff and Katsur provide for such a claim? As I mentioned, they appeal to relevant work in psychology to try to substantiate P2. In particular, they refer favorably to an oft-cited paper by Arthur Greil, which critically reviews the literature on “infertility and psychological distress” [7]. However, among Greil’s critical remarks about this literature is the observation that it focuses almost exclusively on those who seek treatment for their infertility. These people represent less than half of all infertile people in the United States, according to statistics gathered in 1995 [8]. Many of the psychological studies on which Greil comments focus even more narrowly on people who pursue IVF “and other ‘high-tech’ treatment options,” that is, people who are predominantly “white, middle-class urbanites” [7] and who make up only 2% of all treatment seekers [8]. Consequently, the most we can conclude from the literature that Rosoff and Katsur cite is that infertility *can be* devastating (for women in particular). Such a weak claim will not get us very far, however, in showing that oncofertility research is morally worthwhile. One would be hard pressed to justify the expense knowing that the research may only benefit a small number of people.

A further criticism Greil makes of studies about the psychological impact of infertility is that they have poor sample sizes. Unfortunately, this same criticism applies to studies about the desire of cancer survivors to reproduce. Rosoff and Katsur supply the latter studies as evidence in favor of P3, which concerns the extent to which cancer survivors want to procreate. For example, they cite a paper by Leslie Schover and colleagues that describes a survey of cancer survivor’s attitudes on the subject [9]. These researchers

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<sup>4</sup> Our society does not strongly encourage reproduction for everyone; it is anti-natalist toward certain groups, such as poor Black women [17].

conclude that 76% of the respondents who were “childless” wanted to reproduce (and by “childless” they surprisingly mean without biologic children<sup>5</sup>); but there were only 71 of these people, and only 132 respondents in total. Thus, while interesting perhaps, such studies cannot substantiate P3, for which Rosoff and Katsur do not provide sufficient evidence.<sup>6</sup>

The last premise to consider is P4, which says that genetic parenting is one of life’s greatest fulfillments. People often make such a claim about parenting in general; yet for P4 to make sense in the context of Rosoff and Katsur’s argument, it must be specific to genetic parenting. (Rosoff and Katsur do not state the claim very clearly and like Schover et al., sometimes forget that not all parenting is genetic or biological.) P4 is designed to show that cancer survivors have good reason to want to procreate or good reason to be devastated if they cannot procreate. In other words, P4 suggests that the desire mentioned in P3 (and also alluded to in P2) is worthwhile, objectively speaking.

Interestingly, Rosoff and Katsur provide no evidence for P4, which suggests that they believe its truth is self-evident. But is it obvious that biologic parenting contributes to a good life? The answer must be “no” if studies in psychology about well-being and parenting are to be taken seriously. These studies show consistent evidence of “an almost zero association between having children and happiness” or well-being [10]. In other words, they reveal that P4 could, quite simply, be false. Since I doubt many readers will accept that about P4, let me direct our attention to an absolute version of this premise: genetic parenting is *always* fulfilling. Such a statement is surely false. And so perhaps the claim should be that genetic parenting is fulfilling *other things being equal*: that is, only when certain conditions are present or others are absent. The question then becomes, however, what are the relevant conditions? Could one of them be the absence of a history of cancer? While this may sound odd or insensitive, consider that after “battling pediatric cancer, many survivors endure numerous difficulties throughout their lives despite being cured of their disease. Fertility deficits are only one of the problems that they face. . .” [11]. Could it not be that parenting would simply add to the burdens of some (or many) cancer survivors?

My point is not that P4 is false, but rather that evidence needs to be marshaled in favor of it or of any other controversial premise in an argument that defends oncofertility research. Moreover, the evidence needs to be substantial, especially given how many resources are required for this research to happen. Proponents of the science cannot simply assume that most people have a strong procreative instinct, that cancer survivors are among these people, that procreation invariably contributes to a fulfilling life, and that therefore

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<sup>5</sup> Table 4 in their paper puts the total number “currently childless” at 71 (702), but their discussion reveals that ten of these people had stepchildren and two had adopted a child (701). To suggest that these 12 people are childless, and are therefore not parents, is false and potentially very offensive to them and their children.

<sup>6</sup> They also appeal to an article written by Schover alone, which reviews the “psychosocial aspects of infertility and decisions about reproduction in young cancer survivors” [18]. This article simply hypothesizes, however, rather than shows, that infertility is distressing for cancer survivors. Overall, in the oncofertility literature, there appears to be much speculation, and little hard data, about how cancer survivors feel about procreating [19].

infertility is devastating for cancer survivors, even though they may be able to have children in other ways: that is, through adoption or the assistance of a gamete donor.

To be clear, the goal of oncofertility specialists is to preserve the capacity of cancer patients to become genetic parents, not to become parents of any kind. Granted, cancer survivors may confront barriers to becoming non-genetic parents. For example, they may face discrimination, de facto or otherwise, when attempting to adopt children [12]. But why not work to remove these barriers – more specifically to adoption – rather than to preserve the fertility of cancer patients? Perhaps we ought to do both, which is something that some members of the Oncofertility Consortium accept, despite their focus on fertility preservation. Why both, however, rather than just the one that allows for non-biologic parenthood (i.e., adoption)? To offset the bias that our society has toward biologic parenting [6, 13], perhaps we ought to encourage non-biologic parenting for infertile cancer survivors, for infertile people in general, or for everyone for that matter.

This discussion of different forms of parenthood is relevant in assessing whether Rosoff and Katsur's argument is valid. I have shown that they have not established the truth of their premises. Yet even if they had, one might ask whether we should accept their conclusion, (C), on the basis of the premises they give. Does the truth of their premises guarantee the truth of their conclusion? In other words, is their argument valid? I do not think that it is, for at least two reasons. First, assuming that resources are scarce, oncofertility research can only be justified if there are not other more worthwhile ways of allocating the resources that support it. But it is far from obvious that this is the case, especially given that the research may not be as worthwhile as Rosoff and Katsur suggest. Notice that the devastation some cancer survivors feel upon discovering that they are infertile could potentially be overcome through non-biologic parenting. There are psychological studies indicating that among infertile people who do fertility treatments that are unsuccessful, those who choose to adopt children have a greater degree of life satisfaction than those who do not [14, 15].<sup>7</sup> These adoptive parents (and I hope to be one of them soon) could easily have levels of well-being similar to those of infertile people who succeed with fertility treatments.<sup>8</sup> Indeed, their experience may reveal that *adoptive* parenting is “one of life's greatest fulfillments.” Rosoff and Katsur's argument is not valid because it ignores this possibility and the implications it has for the just allocation of resources that are now being spent on oncofertility.

Second, Rosoff and Katsur want to say that the research should proceed with its mandate of preserving the fertility of cancer patients. However, what about women who want to reproduce but need to delay childbearing beyond the time at which they are most likely to

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<sup>7</sup> As with the studies about the desire of cancer survivors to procreate, the sample sizes with these studies are low. But notice that I use them to show only that a certain possibility exists, not that certain claims are true.

<sup>8</sup> Some will say that these people would not have achieved such levels of well-being if they had not had the opportunity to resolve their infertility by undergoing infertility treatment. While it may, however, be true that (unsuccessful) treatment can help with resolving infertility, surely a resolution can come about in other ways. As far as I can tell, it is a myth that infertile people need to go through infertility treatment if only to resolve their infertility (see [8]).

be able to conceive a child without assistance? Rosoff and Katsur's argument does not justify the scientists' focus on the first group of women rather than the second (i.e., on fertility preservation for disease-related infertility rather than age-related infertility [16]). If we can construct versions of P1–P4 that apply to women who will likely suffer from age-related infertility, then presumably we cannot accept Rosoff and Katsur's conclusion that oncofertility research ought to proceed. Consider the following:

- P1) A common complication of being a career-aspiring woman is infertility.
- P2) Infertility "can be [and often is] a devastating experience, especially for women."
- P3) Available data on career-aspiring women suggest that they are no different than the rest of us: many want genetically-related children and infertility is or can be devastating for many of them.
- P4) Genetic parenting is "one of life's greatest fulfillments."
- C) Thus, providing career-aspiring women with the possibility of preserving their fertility is worthwhile, and this in itself justifies research on fertility preservation.

Without a premise stating that we do not owe the same consideration to career aspiring women that we do to female cancer patients, Rosoff and Katsur's argument in favor of oncofertility research is invalid.

## Conclusion

To be sound, an argument in favor of oncofertility research must justify preserving the fertility of *cancer patients* specifically, despite the possibility of them becoming non-genetic parents, and despite the exorbitant cost of the research. Genetic parenthood *may be* essential to the well-being of many cancer survivors. Each survivor *may* even have a right to become a genetic parent (one that entitles him or her to have scientists develop oncofertility techniques using public funds). But neither of these claims is obvious, and each needs to be defended rigorously.

Obviously, the sort of justification I believe is needed for oncofertility research does not presume that genetic parenthood is superior to other forms of parenthood. Such justification has rarely, if ever, been given for the development of other ART, such as in vitro fertilization. But this is no reason not to provide it for oncofertility research. Until that happens, the science will be on shaky moral ground.

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