

Chapter 13

The Lessons of Oncofertility for Assisted Reproduction

Adrienne Asch

A. Asch (B) Albert Einstein College of Medicine, The Center for Ethics at Yeshiva University, Yeshiva University, New York, NY, USA e-mail: asch@yu.edu

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Introduction

Young children, adolescents, and men and women in their prime reproductive years may now survive for decades after cancer. They and their families celebrate these medical advances and hope that after cancer treatment ends, they can resume what Kathryn Conway described as “ordinary life” [1]. When patients and their families learn that the treatments for some cancers can impair their fertility, they may feel that they will not be able to look forward to that ordinary life. No wonder, then, that many adult patients and parents of adolescents will rejoice at the medical and scientific developments that someday might permit them to have their own genetic children.

Like the symposium out of which it grew, this volume addresses the science and the ethics of dealing with cancer-related infertility. If the science and the medicine work, and 5, 10, or 20 years after surviving cancer some people are raising their own children, they may feel that they have had two miracles. They lived when once they might have died; and they have managed to create a new life and to extend themselves into a new generation. But as everyone in this volume acknowledges, there are no guarantees. Even the standard techniques using banked sperm and embryos do not always result in a baby, and using frozen oocytes and cryo-preserved ovarian tissue is still considered experimental.

Several contributors to this volume have explored a host of ethical and psychosocial issues that arise when people face both cancer and infertility. In what follows I extend their ideas and seek to make three main points: first, a great many of the concerns about handling cancer-related infertility apply to people whose infertility stems from other biological factors. Second, the medical response to cancer-related infertility should not remain the primary response, lest it perpetuate an unfortunate societal tendency to use technology to solve non-technological problems. Last, our support for medical cures for cancer, infertility, or anything else should not reinforce the conviction that there is only one kind of “ordinary” or “acceptable” life.

How Is Cancer-Related Infertility Different from All Other Infertility?

Perhaps no disease or disability stirs people’s emotions as does cancer. AIDS and ALS are life-threatening, but in the developed world they are not as prevalent. Heart disease

and stroke combined may cause more deaths than cancer, but heart disease and stroke usually occur in mid- or late-life. Everyone knows someone who has lived with or died from a form of cancer, and perhaps this prevalence in all ages, racial classifications, and socioeconomic strata means that people can readily empathize with patients and their families.

The general population may find it much harder to empathize with the reproductive problems of someone with little-known and stigmatized conditions such as spinal cord injury, cystic fibrosis, multiple sclerosis, or epilepsy [2]. Cancer, and cancer-related infertility, may seem to have come to a person for no reason, out of the blue, as contrasted with infertility that might be a consequence of personal behavior or inadequate health care.

Justifying the emphasis on medical research on oncofertility itself (Chapter 14 by McLeod, this volume), problems inherent in obtaining informed consent for fertility preservation (Chapter 19 by Cohn, this volume, Chapter 33 by Clayman and Galvin, this volume), permitting the retrieval and banking of oocytes prior to cancer treatment (Chapter 17 by Petropanagos, this volume), securing insurance coverage of infertility treatment (Chapter 29 by Campo-Engelstein, this volume), and removing barriers to adoptive parenthood (Chapter 11 by Gardino et al., this volume) illustrate the ethical questions found in this volume. Let me say why I believe that the link to cancer should not determine how we resolve most of them. Instead, their resolution flows from evaluating the essential components of the parent–child relationship.

Along with Carolyn McLeod (Chapter 14, this volume), I question the justification for putting extensive resources into oncofertility research. McLeod questions the empirical basis for the commitment to the research, suggesting that there are many problems with the studies used to support the claims that infertility is psychologically and socially devastating to women and men (especially to women); that biologic parenthood is a chief source of happiness; and that people who have had cancer, like people who have not had cancer, desire genetically related children. The force of her argument is not merely that there might be a weak empirical basis for the psychological harms of infertility. It is possible to listen to those “voices of the infertile” [3] who powerfully articulate their longing for genetic continuity between themselves and their children, and who dream of having a child who embodies their relationship with their partner, and yet maintain that such genetic connectedness is only one facet of any parent–child relationship. I want to go beyond questioning the empirical bases for justifying the oncofertility research to claim, as does McLeod, that the research gets its force from an unquestioned commitment to the moral and social centrality of the genetic basis of the family. Yet contributors to this volume who write about family and the difficulties of family decision-making for their minor children (Chapter 33 by Clayman and Galvin, this volume) note that less than half the children in the United States are living with the two people whose genes they carry.

After the genes have been passed along, what makes a parent–child relationship is the daily acts of physical, emotional, and financial support; the guidance and instruction in

living in the culture and society; the time spent soothing, comforting, explaining, disciplining, and playing. People may indeed derive great pleasure from seeing their own or their relatives' physical characteristics in their children, but appreciating such resemblances is only a fraction of the ongoing involvement in bringing up a child. Consequently, the same considerations that justify concern about the medical research also warrant concern about whether any person could give genuinely informed consent to research or treatment. Cohn (Chapter 19 by Cohn, this volume) points out how difficult it is to convey uncertainties surrounding the treatment for cancer, to ascertain the possibilities that any specific fertility preservation procedure will be effective in the individual case, and to evaluate the risks of delaying cancer treatment against the potential for future genetic parenthood. For a man or woman who already knows that he or she wants children within a few years, there may be very strong incentives to postpone cancer treatment to try to maximize the chances of achieving genetic connection to a future child; if the patient is in a relationship with a partner who expects to be the child's other parent, trying to create and store embryos before treatment may strike everyone as appropriate. But even in the medically easiest procedures of banking sperm or embryos that people expect to use in less than 10 years, how the doctors broach the topic of infertility can influence a patient's decision. If doctors equate infertility with the death of the dream of parenthood, they prevent the patient from imagining that they could contemplate forming a family through adoption or collaborative reproduction.

For the adolescents and young adults and their families who must absorb the news of cancer and then the news that the treatment may destroy genetic parenthood 20 or more years in the future, the difficulties of decision-making about saving fertility may be unique to cancer-related infertility. The treatment for the cancer, not the disease or disability itself, poses the fertility problem. The 14-year-old girl or the 17-year-old boy has been immersed in school, friends, and interests in sports, theater, or computers. Suddenly they learn they might die before college or their first job. If they live, they might not have children. Should they undergo more procedures to keep open the barely imaginable idea of child-raising? If their doctors and parents cannot help them understand that "family" and genetics are not identical, they may feel compelled to subject themselves to procedures they would rather avoid; they may believe they should gratify their parents' dreams of grandchildren when all they want to think about is avoiding any more pain and the anxiety of delaying treating the cancer itself. Alternatively, they may exert what little control they feel they have by opposing their parents and doctors who urge them to skip fertility-saving procedures based on a need for immediate cancer intervention.

Everyone who has spoken of the infertility preservation decision has underscored its time-sensitiveness. The urgency of decision-making so that cancer treatment goes forward quickly strikes me as the major difference between cancer-related infertility decision-making and decisions about treating infertility from other medical causes. There may be no way to give adolescents and their families more time between cancer diagnosis and the beginning of treatment. But doctors must work with parents and their young patients to help them recognize that they might become adoptive parents or step-parents, or that life can be full and rich without children. Doctors must help patients absorb their

own and their parents' shock about the cancer itself, must underscore the uncertainties that they will benefit from effort at fertility preservation, and must confront the panic about lost reproductive capacity. As the only ones with the medical information about what awaits the young patient, they alone must defuse the drama surrounding the possible infertility and guard against overstating the "rescue" potential of novel therapies. Along with Cohn (Chapter 19 by Cohn, this volume) and Clayman and Galvin (Chapter 33 by Clayman and Galvin, this volume), I want to underscore the complexity of helping cancer patients and their families decide how much time, money, and emotion to invest in preserving possible genetic parenthood. But the difficulty of patient decision-making requires that the medical team spend more time in counseling patients, not only about the medicine but also about adoption and collaborative reproduction as legitimate means of forming parent-child relationships.

Contributors to this volume do not hold a unanimous view on whether there should be different policy responses to infertility following cancer treatment than to any other basis for infertility. Angel Petropanagos (Chapter 17 by Petropanagos, this volume) maintains that any woman, not just those facing cancer treatment, should be allowed to freeze her oocytes for future use. Petropanagos argues that the women whose infertility results from delaying childbearing for educational, financial, or career reasons have no more "choice" than the women who lose reproductive capacity from treating their cancer. Egg-freezing might lessen women's sense of having a "biological clock," and could give them some of the freedom men have always enjoyed about whether and when to reproduce. However, as I have discussed elsewhere [4], if many women freeze their eggs, this could divert attention away from the social structures that pressure women to delay child-bearing in the first place. Here is one instance where I think cancer-related infertility may merit sui generis policy.

A woman of 17, 25, or 33 years of age who discovers that she will lose her fertility in 2 or 3 weeks following cancer treatment has had no reason to bank her eggs. Although she may have delayed childbearing and parenthood for many reasons, before the diagnosis she expected that she still had several years of fertility left to her. There is more than a short "right" time for women to become genetic mothers if they so choose, but the woman infertile after cancer treatment has suddenly found that she has no more time to reproduce with her own genetic material. Treating an unexpected disease, not a maladaptive set of social institutions, has led to her infertility. By contrast, egg-freezing for age-related infertility uses biology to resolve a socially created problem. There is nothing inevitable or essential about the typical educational and work arrangements in the US, Canada, and other advanced societies. Societal endorsement of egg-freezing for women's biologically expectable, age-related infertility tacitly accepts unjust social arrangements and suggests that individual women should pay the physiologic and financial price for practices that favor men's lives.

Campo-Engelstein argues that treatment for cancer-related infertility is analogous to other treatments (wigs for hair loss and reconstructive surgery after mastectomy) that are commonly regarded as medically necessary. Although breast augmentation or diminution are usually considered elective cosmetic procedures and therefore not covered by health

insurance plans, the surgery following cancer puts them in a different category, a response to an underlying illness. The same rationale warrants covering the costs of cancer-related fertility preservation through health insurance. The infertility is an inevitable part of some cancer treatment, beyond an individual's control. Campo-Engelstein makes a compelling case, but virtually all biologically based infertility is beyond an individual's control. As long as society does not condition receipt of health insurance coverage on alleged "responsibility" for illness, the costs of infertility treatment are arguably no less worthy of health insurance coverage than the costs of heart surgery that might have been prevented by diet and exercise.

Nonetheless, I would not endorse an automatic health insurance coverage of infertility treatment for cancer-related or any other biologically based infertility unless similar subsidies were available to people who chose to form families through adoption. Treatments for infertility do not usually restore the functioning of a body system; instead, they use the tools of science and medicine to create a child genetically related to at least one of the people who will raise that child. In keeping with my emphasis on the social, and not the genetic, component of the parent-child relationship, I would avoid coverage for only biologically based family creation.

Shauna Gardino (Chapter 11 by Gardino et al., this volume) looks at the barriers to adoptive parenting that have confronted cancer survivors. The vagaries of the adoption process, along with the scarcity of infants available for domestic adoption, lead many infertile people to risk medical procedures. Potentially intrusive home studies, adoption agency rules about parents' age, income, health, or disability status [2] can discourage those who might be happy to avoid fertility treatment and pursue adoption. The attention given to changing adoption practices that affect cancer survivors is laudable, but people with many other illnesses and disabilities deserve the same recognition as eligible potential parents. The cancer survivor and his wife may meet all the criteria of an adoption agency that is willing to look beyond the label of a medical diagnosis. But the same can be said for a woman with a spinal cord injury and her non-disabled husband [2]. They, too, deserve the careful scrutiny of any other would-be adoptive parents, but prejudices about how a parent's mobility, visual, psychiatric, or hearing impairment will adversely affect a child still thwart people with disabilities from attaining their parenting goals.

If the purpose of becoming a genetic or an adoptive parent is to have a deep, enduring, hopefully long-lasting relationship with a growing child, the matter of life expectancy after cancer cannot be ignored. Should someone with a life expectancy of less than 10 years undertake infertility treatment or adoptive parenting? This is a troubling question worthy of more sustained discussion by the oncofertility community. Parenting is more than procreation, the creation of genetically connected offspring. Rather than limit eligibility for adoption or infertility services based on predicted longevity, I would urge the oncofertility community to explore with would-be parents the provisions they will make for the care of their children if they cannot survive to see their child reach adulthood. A loving parent-child relationship, supported by other family and friends may provide the foundation for a child despite the loss of a father or mother before he is

grown. But if parenting is, or should be, about forming a special relationship with a child, it seems reasonable to suggest that cancer patients with a life expectancy of less than a few years are not going to be able to help a child get started in life. Yes, children through the ages have lost parents during their infancy; mothers have died in childbirth, and fathers in war. That children survive such parental losses is not a justification for creating or adopting a child if one believes that his time is short.

Parenting gives an unparalleled opportunity to guide someone and foster her growth. Infertility treatments and adoption provide people who cannot reproduce without assistance to bring children into their lives. Parenting, however, is not the only way to make a difference to a young person. Teachers, relatives, and family friends often play crucial roles in children's lives, and many adults discover how fulfilled they can be in relating to children as less than a parent, far more than a casual acquaintance. The push for preserving fertility after cancer or other health problems should not obscure the richness of adult-child relationships beyond the parents.

For the same reasons that I urge health professionals to remind the infertile that genetic connection is not the only way to become a parent, I urge us all to remember that adults and children need a variety of connections. The infertile cancer survivor deserves social and professional support for finding non-parenting roles in children's lives. Rather than promoting options and choices for people after cancer, the emphasis on fertility preservation could inadvertently lead people to feel like failures if their efforts did not yield a genetically related child. The goal of oncofertility should not be enshrining one way to fulfill oneself, and should not lead anyone to conclude that there is only one "ordinary" or acceptable life.

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