

Infertility, cancer, and changing gender norms

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Abstract

Introduction Recent improvements in cancer detection, treatment, and technology have increased survivorship rates. These same life-saving treatments, however, can lead to infertility or sterility. Oncofertility, an emerging field at the intersection of cancer and oncology, centers on providing cancer patients with the potential to preserve their biological fertility.

Methods We examine the history of how men and women have been treated for infertility and analyze contemporary studies of how women without cancer respond to infertility.

Results Both female and male cancer patients and survivors value their fertility, although there is conflicting evidence on the degree to which women and men value fertility. Some studies have found that women and men value their fertility equally while others found that women value their fertility more than men. Gendered norms around fertility and parenthood seem to be changing, which may minimize these discrepancies.

Discussions/conclusions Although oncofertility is a nascent field, infertility is a historically relevant medical condition that is characterized by gendered narratives and norms. An

analysis of the historical evolution of the understanding and treatment of infertility leads insight into modern conceptualizations of infertility both generally and in the case of cancer. Understanding these historical and current gendered influences helps to define the current context in which cancer patients are confronting potential infertility.

Implications for cancer survivors The insight gained from this analysis can be used to inform clinical practice, offering guidance to healthcare providers approaching cancer patients about potential infertility, regardless of gender.

Keywords Oncofertility · Infertility · Gender · History · Cultural narratives

Introduction

Although cancer is generally perceived as a condition affecting people past their child-bearing years, nearly 10% of those diagnosed are under age 45 [1]. But while more aggressive treatments have meant more people survive cancer, these treatments have also resulted in infertility or sterility for some. Given the numbers of children and adults within their child-bearing years diagnosed with, treated for, and surviving cancer, fertility concerns have emerged as an important issue to cancer survivors and their families. Oncofertility, an emerging field at the intersection of cancer and fertility, is working to address potential infertility as a result of cancer treatment [2]. In one study of cancer survivors, 76% of those who were childless expressed a desire to have children in the future [3]. Impaired fertility as a result of cancer treatment has psychological as well as physiological effects. Though reproduction is valued by both women and men, there is conflicting evidence on the

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relative value of fertility for female and male cancer patients and survivors. We begin this essay by reviewing this literature. We then frame differences between men and women cancer patients by examining the history of how men and women have been treated for infertility and by analyzing contemporary studies of how women without cancer respond to infertility. Our goals in this paper are to historically situate infertility and to uncover gender narratives and norms that have contributed to this contemporary discrepancy. The insight gained from this analysis can, we hope, be used to inform clinical practice, offering guidance to healthcare providers approaching cancer patients about potential infertility, regardless of gender.

Overview of existing research

Initial studies of fertility concerns among cancer patients and survivors showed women valued fertility to a greater extent than men. In 1987, Wasserman et al determined that attitudes toward possible sterility differed dramatically between female and male Hodgkin's survivors, with females expressing less concern about their fertility than males [4]. Five years later, Zelter's literature review concluded that women sought more information and evaluation of their fertility status than men [5]. Schover et al (1999) followed with another literature review, hypothesizing from gathered data that women were more distressed over infertility, more concerned about having children, and more likely to see parenthood as an integral part of their life compared to men [3]. Finally, Patridge et al (2004) found women would sacrifice the efficacy of cancer treatment to lessen their chances of infertility or sterility; if given a choice, young women with early-stage breast cancer would choose a less toxic regimen of chemotherapy even if it conferred slightly less protection from cancer recurrence [6].

However, a handful of studies recognized male cancer patients and survivors valued their fertility as well. A 1990 study by Reiker et al of 153 testicular cancer survivors indicated that distress about infertility was prevalent among men, particularly those whose cancer treatments were likely to severely impair their fertility [7]. Similarly, a 2003 study by Green et al confirmed that infertility could cause long-term distress among men with cancer [8]. The literature regarding fertility concerns among male cancer patients, however, is scarce when compared to the number of studies demonstrating the importance of fertility among female cancer patients; nonetheless this data should not be ignored. A growing body of more recent literature reveals fertility concerns among male cancer patients, concluding that gender differences in fertility concerns among cancer patients may not be as prominent as once thought.

A 1999 study by Schover et al, which used a questionnaire to examine 283 young cancer survivors, found about 80% of cancer survivors viewed themselves positively as actual or potential parents, with no observed gender-related differences in the wish to have children or distress about fertility [3]. Similarly, a 2004 study by Zebrack et al using semi-structured interviews showed both men and women wanted to have children in the future [9]. Finally, an exploratory qualitative study by Crawshaw (2010) revealed that fertility matters affected identity, well-being, and life planning as well as reproductive function, regardless of gender [10].

Our literature review of gender differences in fertility concerns among cancer patients indicates conflicting evidence, a reflection that gendered differences may be changing. While older studies conclude that female cancer patients value their fertility more strongly than male cancer patients, newer research suggests men consider infertility just as distressing as women. These disparate conclusions can also be explained by differing methodologies; the aforementioned studies range from semi-structured interviews to questionnaires to literature reviews. Although the studies are rooted in distinct and differing methodologies, making accurate comparisons between them difficult, they nonetheless suggest that the gender differences in how men and women view infertility are shifting, with men now regarding infertility as a result of cancer treatment as an important issue in their post-cancer lives.

Women and infertility

If this literature is noting a decrease in the discrepancy between how women and men view infertility, how did the discrepancy arise? Historically, infertility was regarded by in large as a feminine condition. Though motherhood had earlier been a principal role for women, during the nineteenth century it increasingly became the defining role for women, especially white middle-class women [11, 12]. Biological parenthood rather than household composition came to define a family, and thus being a mother increasingly meant bearing one's own children. As part of this shift, biological motherhood was increasingly regarded as the primary and principal role of women—in contrast to women in colonial America, where motherhood, though important, was seen as only one of a woman's roles [12]. Being a mother, especially through pregnancy, began to be more strongly tied to being a woman. This change in the stress placed on biological motherhood as the core identifier for femininity, along with the rise in the profession of gynecology, prompted a change in the way involuntary childlessness was viewed, both popularly and medically. What had been regarded as barrenness, a

personal misfortune, became infertility, a treatable condition. But though infertility became a recognized medical condition, patients seeking treatment for it were nearly all female [12]. As the twentieth century wore on, increasing numbers of women sought medical expertise to enable them to conceive, with a sharp rise in infertility treatments accompanying the baby boom following World War II. During this intense pronatalist period in American history, to not be pregnant or have children within 2 years of marriage marked some women as odd—possibly even suggesting a lack of femininity. This tie between a woman's ability to conceive and her femininity, though ebbing a bit in the 1970s, remained strong through the course of the twentieth century [12, 13].

The cultural connection between a woman's reproductive ability and her feminine identity has strong historical foundations in how women have been treated for infertility, foundations that continue to frame cultural conceptions of femininity as well as individual women's conception of themselves as female. Women have, and continue to, internalize their infertility. The contemporary literature on women without a cancer diagnosis but with impaired fertility reveals a significant amount of stress and depression due to their condition. Women who are infertile but otherwise healthy are twice as likely to be depressed as fertile healthy women; indeed, these women report levels of psychological distress comparable to women with life-threatening illnesses [14–16]. In learning of their infertility, women often experience a profound shock to their sense of themselves, resulting in a challenge to their conception of identity as female [17].

What happens, then, to a woman's conception of herself when the option for biological motherhood is impaired or taken away because of her cancer diagnosis or cancer treatment? The existing literature on women whose fertility is impaired due to cancer treatment reveals similar psychological stress; for these women, "psychological distress may result from, not only the loss of the physical ability to conceive, but also a symbolic loss of the option or idea of fertility, regardless of whether this would have been acted upon or achievable" [18]. The American Society of Clinical Oncology (ASCO) found that "surveys of cancer survivors have identified an increased risk of emotional distress on those who become infertile because of their treatment" [19]. One study on young women with breast cancer found that "fertility concerns may complicate" their "treatment decision-making process" and that there is evidence these young women "may experience greater psychological distress and more difficulty with adjustment to the diagnosis and treatment of breast cancer" [6]. This actual or symbolic loss has potentially great implications for a woman's perceptions of herself as female, for motherhood is a culturally significant role most women

see themselves in and which cancer potentially interrupts. Women whose cancer treatments threaten their fertility may still want the experience of motherhood, most often biological motherhood [19]. This equation of femininity with reproductive ability remains culturally resonant. Women today, as in the past, quite often tie their feminine identities to their reproductive capabilities; a cancer diagnosis is a recent, and additionally culturally powerful, component of a longer story concerning women, infertility, and medical treatment.

Men and infertility

But even as the concept of barrenness gave way to infertility for women in the nineteenth century, very few doctors asked to examine a patient's husband, as most physicians still considered it rare for a virile man to be infertile [12]. Though by the late nineteenth century some gynecologists began calling for husbands to be examined when wives came seeking a cure for their childlessness, male fertility continued to be connected to virility through the twentieth century—even though physicians acknowledged that the viability of the semen was an identifiable and common factor [20]. Even with the knowledge that men were infertile as often as women, a gender difference in treatment continued during the twentieth century. So while the physiological knowledge was there and the understanding that men were as likely to be infertile as women was available, women continued to be the ones most often treated because they most often sought the initial medical intervention. Even if a physician could not find a physiological reason on the woman's body, both the woman and the physician frequently believed the impairment was with her body. From the nineteenth century to the present, women have most commonly sought medical intervention for infertility, often doing so in order to spare their husbands from possible humiliation—a humiliation based on the cultural idea that an infertile man was an impotent man [12, 13].

Virility remains a significant component of cultural conceptions of masculinity and men's gendered identities today. Sexual prowess is often seen as a way of proving one's masculinity. Furthermore, the male genitals are generally central to a man's coherent sexual identity, and are associated with stereotypical masculine traits like "strength" and "courage" [21, 22]. Because of the personal, as well as social, significance of the male genitals, having "misfunctioning" (e.g. impotent, prematurely ejaculating, infertile) genitals or genitals that look "abnormal" (e.g. small penis, missing a testicle) can diminish men's sense of masculinity [23]. This trend holds true for men facing cancer, especially those with cancer affecting the genitals:

in one study, college men listed losing a testicle to cancer as the second most humiliating experience for men. Furthermore, a qualitative study on men with testicular cancer found that definitions of masculinity continue to be strongly tied to sexual performance and the appearance of “normal” genitals, both of which can be threatened by cancer and cancer treatments [21].

Whereas the centrality of virility and male genitals to men’s sexual identity is clearly supported in the literature, the importance of fertility for men—the desire to have biological children and the role fertility plays in their identity—is not just ambiguous, but is often contradictory [21]. As previously discussed, some studies found male cancer patients value their fertility as much as female cancer patients whereas other studies show that women value their fertility much more than men. Much of the broader literature on infertility in the general population, not just cancer patients, supports the latter finding. In his interviews with mainly white, middle-class, heterosexual married couples facing infertility, Arthur Greil found the husbands were more likely to view the experience of infertility as disappointing but not as a threat to their identity [24].¹ Wives, however, saw infertility as devastating, something that spoiled their identities and signified a failure in their roles of woman, wife, and mother [24]. Furthermore, both qualitative and quantitative studies show that women react more negatively to infertility (e.g. have lower self-esteem, blame themselves for their infertility, feel defective, etc.) than men [24]. Even when the couple is suffering from male factor infertility, most of the literature concludes that this does not seem to change men’s response to infertility [24].

Given that infertility is not as devastating for men as impotence or abnormal genitals, it is not surprising that a diagnosis of sterility ranks lower (in fifth place) on the list of the most humiliating experiences for college men than experiences that are more closely connected to sexual performance and the appearance of “normal” genital [23].² It is worth noting that men older than traditional college age students (18–22 years old) may have come up with a different ranking; while college age men are typically trying to avoid fatherhood and consequently do not value fertility as much at this stage in their lives, older men are probably

more interested in becoming a father and thus may find a diagnosis of sterility more humiliating.

While sterility and infertility may not top the list as the most humiliating experience for young men, they are still negative experiences. A large reason for this is the close relationship between men’s virility and fertility [25]. The historical association of infertility with impotence and the importance of virility to current conceptions of masculinity result in cultural understandings of infertility as an indicator of emasculation. Indeed, “the ability to biologically father one’s children remains a hallmark of one’s manhood, and infertility remains a source of masculine shame” [26]. Specifically, questions about the viability of sperm production incite questions about the viability of masculinity [21, 26]. This association is reflected in the secrecy and stigma surrounding heterosexual couples using sperm donation and results in practices like “matching” sperm donors to the physical traits and characteristics of the social father to hide his infertility [26, 27].

In addition to threatening masculinity, infertility may adversely affect men because it leaves their desire for biological children unfulfilled. Yet, this reason probably plays a smaller role for men than for women. The cultural pressure for women to have biological children and the fact that motherhood is an important part of many women’s identity are thought to be a significant factor in why infertility is so devastating to women. That “[t]here is, in American society, no ‘fatherhood mandate’ with the same force and intensity as the ‘motherhood mandate’” may explain, at least in part, men’s less strong reaction to infertility [24].

While there is still less pressure for men to be biological fathers compared to the pressure women feel to be mothers (at least in the U.S.), men today play a much more active role in their children’s lives than even a generation ago. We see this change reflected in new concepts and policies. For example, the concept of a stay-at-home dad is relatively recent; today there are approximately 143,000 stay-at-home dads [28]. Men’s involvement in primary caretaking of children is also seen in policies like extending maternity leave to men through paternity leave. A recent study shows that 89% of men took some time off after the birth of their child [29]. Men’s commitment to caring for their children remains even when heterosexual couples separate; the number of single fathers has increased from 400,000 in 1970 to 2.3 million in 2006 [28].

Men’s increased involvement in their children’s lives shows not only the significance of fatherhood for many men, but also that men’s active participation in their children’s lives is becoming more socially acceptable and expected. Gender norms surrounding fatherhood are changing, influencing the value men place on becoming biological fathers. Fatherhood today seems to play a greater

¹ White, middle-class, heterosexual married couples are the most common participants of many empirical studies on infertility in part because they are the social group most likely to seek out infertility treatment. In the last handful of years, however, more research has been done on people of color and infertility. See, for example, Becker et al., Jain, and White et al.

² Having a rectal exam ranks fourth. While this experience does not directly deal with male sexuality, being penetrated is usually associated with women, which is in part why this experience is humiliating.

role in men's identity and their vision of life. This social change helps explain the mixed results on the importance of fertility to male cancer patients as illustrated in the surveys. We are in a time of transition between active fatherhood and traditional male gender roles. The current discrepancies in data mirror this transition, as some studies show that men are less interested in their fertility than women and other studies reveal an equivalent interest in fertility. If men's interest in active fatherhood continues to grow, we anticipate that in the future, these analyses will reflect a decrease in gender discrepancy regarding the value of fertility.

Clinical implications and conclusions

Understanding the historical differences in medical treatment and social perceptions of infertility contextualizes contemporary cancer patients' views on this topic. Studies consistently show that fertility is very important to female cancer patients, and, while the results for male cancer patients are mixed, many men do strongly value their fertility. Unfortunately, these studies are often not translated into clinical practice by health care providers. Instead, many providers continue to make assumptions "based on the patient's age, sex, diagnosis, culture, and partnership status without checking with the patient" [30]. Furthermore, providers' personal characteristic (e.g. age, sex, etc.) also influences whether they discuss fertility preservation treatment with their patients; a recent study found that female oncologists were more likely to refer their patients compared to male oncologists. While discussions and referrals for fertility preservation among adult cancer patients are improving, they remain suboptimal: only 47% of providers always or often refer cancer patients of childbearing age to a reproductive endocrinologist or infertility specialist. [31]. Health care providers need to openly address potential infertility as a consequence of cancer treatment so their patients are informed about fertility preservation options. Such a discussion with both men and women regarding the potential impact of cancer treatment on their fertility will further decrease the gender discrepancy concerning fertility.

References

1. Horner, MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlander N, Altekruse SF, Feuer EJ, Huang L, Mariotto A, Miller BA, Lewis DR, Eisner MP, Stinchcomb DG, Edwards BK, editors. SEER Cancer Statistics Review, 1975–2006, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2006/, based on November 2008 SEER data submission, posted to the SEER web site, 2009.
2. Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. *N Engl J Med*. 2009;360(9):902–11.
3. Schover LR, Rubicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer*. 1999;86:697–709.
4. Wasserman AL, Thompson EI, Wilimas JA, Fairclough DL. The psychological status of survivors of childhood/adolescent Hodgkin's Disease. *AJDC*. 1987;141:626–31.
5. Zelter LK. Cancer in adolescents and young adults: psychosocial aspects in long-term survivors. *Cancer*. 1993;71 Suppl 10:3463–8.
6. Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, et al. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004;22:4174–83.
7. Rieker PP, Fitzgerald EM, Kalish LA. Adaptive behavioral responses to potential infertility among survivors of testis cancer. *J Clin Oncol*. 1990;8:347–55.
8. Green DH, Galvin H, Horne B. The psycho-social impact of fertility on young male cancer survivors: a qualitative investigation. *Psychooncology*. 2003;12:141–52.
9. Zebrack BJ, Casillas J, Nohr L, Adams H, Zelter LK. Fertility issues for young adult survivors of childhood cancer. *Psychooncology*. 2004;13:689–99.
10. Crawshaw MA, Sloper P. 'Swimming against the tide'—the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. *Eur J Cancer Care*. 2010 Jan 19, Epub ahead of print.
11. Apple RD, Golden J. Introduction. In: Apple RD, Golden J, editors. *Mothers and motherhood: readings in American history*. (PAGES) Columbus: Ohio State University Press; 1997.
12. Marsh M, Ronner, W. *The empty cradle: infertility in America from Colonial times to the present*. Johns Hopkins University Press. 1996.
13. May ET. *Barren in the promised land: childless Americans and the pursuit of happiness*. New York: Basic Books; 1995.
14. Davis DC, Dearman CN. Coping strategies of infertile women. *J Obstet Gynecol Neonatal Nurs*. 1991;20(3):221–8.
15. Domar A, Zuttermeister P, Friedman R. The psychological impact of infertility: a comparison of patients with other medical conditions. *J Psychosom Obstet Gynaecol*. 1993;14(Special Issue):45–52.
16. Lukse MD, Vacc NA. Grief, depression, and coping in women undergoing infertility treatment. *Obstet Gynecol*. 1999;93(2):245–51.
17. Letherby G. Challenging dominant discourses: Identity and change and the experience of 'infertility' and 'involuntary childlessness'. *J Gend Stud*. 2002;11:277–88. ref. on pg. 279.
18. Carter J, Rowland K, Chi D, et al. Gynecologic cancer treatment and the impact of cancer-related infertility. *Gynecol Oncol*. 2005;97:90–5.
19. Lee SJ, Schover LR, Partridge AH, Patrizio P, Wallace WH, Hagerty K, et al. American society of clinical oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*. 2006;24(18):2917–31.
20. Blech GM. *The Practitioner's guide to the diagnosis and treatment of diseases of women*. Chicago: M. Robertson; 1903.
21. Gurevich M, Bishop S, Bower J, Malka M, Nyhof-Young J. (Dis) embodying gender and sexuality in testicular cancer. *Soc Sci Med*. 2004;58:1597–607.
22. Szasz I. Masculine identity and the meanings of sexuality: a review of research in Mexico. *Reprod Health Matters*. 1998;6(12):97–104.
23. Mormon MT. The influence of fear appeals, message design, and masculinity on men's motivation to perform the testicular self-exam. *J Appl Commun Res*. 2000;28:81–116.
24. Greil AL. *Not yet pregnant: infertility couples in contemporary America*. New Brunswick: Rutgers University Press; 1991.
25. Inhorn MC. Sexuality, masculinity, and infertility in Egypt: potent troubles in the Maritaland medical encounters. Special Issue on

- “African Masculinities,” Lahoucine Ouzgane, editor. *Journal of Men’s Studies*. 2002;10(3):343–359.
26. Daniels CR. *Exposing men: the science and politics of male reproduction*. New York: Oxford University Press; 2006.
 27. Becker G, Castrillo M, Jackson R, et al. Infertility among low-income Latinos. *Fertil Steril*. 2006;85(4):882–7. 3.
 28. U.S. Census Bureau. Press release: Father’s day. http://www.census.gov/Press-Release/www/releases/archives/facts_for_features_special_editions/006794.html. Published June 12, 2006. Accessed March 11, 2010.
 29. Nepomnyaschy L, Waldfogel J. Paternity leave and fathers’ involvement with their young children: evidence from the American ECLS-B. *Community Work Fam*. 2007;10(4):427–53.
 30. Horden AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Med J Aust*. 2007;186(5):224–7.
 31. Quinn GP, Cadaparampil ST, Lee JH, Jacobsen PB, Bepler G, Lancaster J, et al. Physician referral for fertility preservation in oncology patients: a national study of practice behaviors. *J Clin Oncol*. 2009;27(35):5952–67.