Chapter 10
Oncofertility and the Social Sciences

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Due to breakthroughs in medical technology and more aggressive forms of cancer treatment, today most people diagnosed with cancer survive. In 2000, over 2.5 million adults of childbearing age were survivors of cancer [1,2]. And by 2010, it is estimated that one out of every 250 adults will be a survivor of childhood cancer [3,4]. The more aggressive forms of treatment that have made it possible for more people, particularly those diagnosed at younger ages, to survive cancer, however, also often impair an individual’s fertility. The field of oncofertility has emerged as a way to address lost or impaired fertility in those with a history of cancer. Biomedical research in this area is active in developing new ways to help those afflicted preserve their ability to have biological children. Oncofertility is also an interdisciplinary field that bridges biomedical and social sciences and examines issues regarding an individual’s fertility concerns, options, and choices in light of cancer diagnosis, treatment, and survivorship. Although the potential effects of cancer treatment on an individual’s fertility are well documented, the rate and extent of fertility impairment among those who have undergone cancer treatment are not fully known. Similarly, within the social sciences, how cancer patients are affected by infertility in their day-to-day lives and the impact on their sense of self have been largely overlooked. Improved survivorship rates over the last several decades, however, mean that cancer-related infertility is an issue that will become a concern for an increasing portion of the population along with their partners and families.

Biomedical and social science research have largely been separate areas of scholarship with little discussion or inquiry across fields. However, a recent issue of Science implored that “the successful application of new knowledge and breakthrough technologies, which are likely to occur with ever-increasing frequency, will require an entirely new interdisciplinary approach” (p. 1847) [5]. Similarly, the interdisciplinary nature of oncofertility recognizes that understanding the social dynamics, institutional behaviors, and structural factors that envelop emerging technologies are not secondary research issues but require careful empirical inquiry as technologies are developed because the surrounding social environment influences and is affected by how those technologies are integrated into society and used by individuals and institutions. Including social science research as a constitutive part of oncofertility will help to broaden understanding within the
health care community regarding cancer patients’ concerns about their fertility and future family plans. Specifically, social science can help to uncover how cancer patients, along with their families and physicians, make health care decisions that are cognizant of fertility concerns and how these decisions are couched in specific social, legal, economic, and cultural contexts. Social science insight will be vital to the field of oncofertility as it grows. The intent of this chapter is to highlight some important first steps that build upon existing scholarship within the social sciences, including medical sociology, gender studies, racial/ethnic studies, communications research, and stratification.

Studying Cancer Within the Social Sciences

There are few health issues that have received as much attention within biomedical sciences, the political arena, and the media as cancer. As a leading cause of death, cancer receives much in the way of government-sponsored and private research monies, volunteer efforts, political advocacy, and public interest. Social scientists have well considered many aspects of health and illness, including the stigma associated with illness (particularly mental illness); disparities in health care prevention, treatment, and outcomes; the organization and access to health care systems; and issues of professionalization and expert knowledge within the health care community. Curiously, less attention has been paid to cancer as a realm of inquiry. Tritter, in fact, calls for a distinct “sociology of cancer” because cancer challenges how we think of disease and illness [6]. For one, it is a diffuse category that includes over 200 variants recognized by histopathologists and its treatment cuts across many medical disciplines, including surgery, oncology, palliative care, and occupational therapy, resulting in a highly complex and blurred network of caregivers and health care institutions treating a single patient [6]. It is not always clear which medical professional is in “charge” of a particular issue, particularly who should advise cancer patients regarding potential fertility impairment.

Cancer also challenges how we think of a “sick” person [6]. Many cancer patients do not exhibit feelings of illness upon diagnosis (although this varies with the form). It is often the treatment, including chemotherapy and radiation therapies, that results in sickness. Moreover, a cancer diagnosis itself is often a transformative experience in a person’s life akin to other major illness (such as mental illness, HIV/AIDS, or muscular sclerosis) whereby the illness becomes a master status. But unlike most other illnesses and disorders, cancer becomes a prominent part of an individual’s biography, even after someone is successfully “cured.” People who have overcome cancer are forever viewed as “survivors.”

Cancer is a transformative experience in an individual’s life not only because of the survivorship status it confers, but because of the secondary health issues that can be caused by the cancer or its subsequent treatment, including impaired fertility. As a broad discipline, oncofertility intends to look at reasons leading to fertility impairment and to develop ways to safeguard a cancer patient’s fertility. The aim of
oncofertility is also to explore how infertility impacts those with cancer, their families, and their future family goals and plans. The perspective of oncofertility is that fertility and cancer combine to create a unique set of issues to be researched. It is not simply that cancer patients have a different set of options than non-cancer patients in terms of becoming a parent, but rather having cancer qualitatively alters how one makes choices regarding family planning and goals. Undoubtedly, there is a host of issues that social scientists can tackle within the realm of oncofertility, but important first steps would be to look at health care decision making regarding cancer and fertility preserving treatment choices because of the impact of cancer and related infertility has on the lives of those with cancer and their families. Moreover, social science inquiry within oncofertility should be particularly attuned to issues of gender and race/ethnic diversity because of the implications for disparities in the experiences of cancer survivors in terms of reaching family and parenting goals.

### Gender and Oncofertility

An important avenue for research within oncofertility would be to look at gender differences in the fertility concerns of male and female cancer patients, differences in the health care decisions men and women make regarding whether or not to take steps to pursue fertility-conserving treatment options (such as sperm banking or emergency IVF), and the impact of infertility on men’s and women’s survivorship experiences. Historically, men with cancer have had more effective options in terms of safeguarding their fertility. Men who have reached puberty have long had the option of cryopreserving sperm for later use (as was done by Lance Armstrong when diagnosed with advanced testicular cancer). Women have had far less successful options (see Appendix, this volume, for overview of options). For those with cancer of non-reproductive organs, shielding ovaries during radiation treatment or emergency in vitro fertilization (IVF) are the most common options. However, shielding only has a limited effect and emergency IVF delays cancer treatment and can only be performed on those who have reached puberty. Because emergency IVF requires fertilization and results in an embryo, the decision is also fraught with ethical issues (e.g., What happens to fertilized embryos if the woman does not survive? What if a married couple divorces prior to the embryos being used? What about women who do not have a partner?). Although women who have been diagnosed with cancer have much improved chances of being able to bear children today, the chances of post-diagnosis parenthood is still far greater among male cancer patients [7]. The field of oncofertility emerged as a way to address this gender inequity by developing more options for women. Yet, there is little insight into “what survivors know about their own fertility status, how and when they obtain information regarding the impact of cancer treatment on their fertility, and how they respond to that information” (p. 869) [8]. Research could look at differences in the fertility concerns of men and women at the time of diagnosis as well as a comparison of the health care decisions that men and women regarding fertility-conserving treatments.
One major question that remains unanswered is how cancer patients learn about possible fertility impairment and fertility-conserving treatment options, particularly in the context of the doctor-patient relationship, and how this may differ by gender. While those facing cancer may turn to the Internet or other sources for information, most still rely on their doctors as their primary information source [9,10]. The small body of research on patient-physician interaction regarding cancer and fertility (most of which exists outside of the social sciences) points to rather worrisome findings. In several studies, many, if not most, respondents did not recall having discussions with their physicians regarding the possible impact of cancer treatment on their fertility. Less than 60% of young adults who have survived cancer could recall discussions of possible infertility due to cancer treatment [11–14]. Although studies of adult survivors of childhood cancer often rely on recollections of conversations held years earlier, results for those diagnosed as adults are similar. Only 72% of younger women with breast cancer discussed fertility with their doctor in one study [15], and half of physicians in another study reported “rarely” or “never” addressing sperm banking or infertility issues with male cancer patients at risk for infertility [16]. Also, cancer patients who want fertility information do not always get adequate information. Younger women dealing with breast cancer have reported receiving insufficient information on the impact of cancer treatment on their fertility or what could be done [17].

So while a lack of information regarding fertility seems to be a common feature of most cancer patients’ diagnostic and treatment experiences, what is not known is how men and women facing fertility-threatening cancer treatment interact with health care staff, if this differs by gender, and how these potential gender differences affect the flow of fertility-related information. In particular, there are almost no direct comparisons of men and women in terms of the likelihood of discussing fertility or treatment options with a doctor. Research has shown that the gender of the physician can alter what topics or issues are brought up with male and female patients [18]. Further, one study of proactive fertility-related behaviors of men who have undergone treatment for testicular cancer suggests that some behaviors (i.e., fertility testing) were more likely to occur among the higher educated, suggesting “that physicians identify more closely with the men with whom they share status characteristics and, therefore offer them more encouragement or information” (p. 353) [19]. This may indicate that when doctor and patient share status similarities (such as gender), physicians may be more likely to discuss such sensitive issues. Because men still outnumber women among doctors, women may be disadvantaged in discussing fertility with a physician because men are more likely to have a physician of their same gender. Understanding how fertility information is shared between physician and patient and how this may differ by gender is vital because it has been found that concerns over infertility can alter treatment decisions [13,15], and the biggest barrier to undergoing fertility-conserving treatment is a lack of information (even for relatively simple procedures such as sperm banking) [20].
Gender and the Experience of Infertility

A key part of oncofertility involves looking at the post-treatment fertility of cancer survivors and its impact on their lives. Those who have investigated the impact of infertility on the concerns of cancer survivors from a social science perspective tend to focus on a group of cancer survivors (e.g., breast or childhood cancer survivors), which is often limited to a particular gender and with most focusing on women. This research has shown that for some women infertility can be as distressing as cancer itself [1,21,22]. Very few studies exist that compare men’s and women’s experiences with infertility directly (for exception, see [1]), leading to a lack of understanding within the social sciences of how men and women experience infertility post-cancer.

More generally, research has looked at the emotional distress that often accompanies infertility (see [23] for review) and suggests that women and men do in fact experience infertility differently. Women’s infertility tends to challenge their status or self-image as a “complete” woman, which for many involves being a good wife and mother, whereas male infertility calls into question sexual potency and masculinity [23]. In one study of infertile couples, Clarke et al. found that both men and women saw parenthood as a mark of adulthood and that infertility called into question their gendered self-image. However, men were more concerned with how infertility called into question their masculinity and sexual prowess, whereas women placed greater emphasis on their bodies in needing of repair, which stemmed from the fact that medical interventions are often aimed at women in infertile couples.

As a field, oncofertility recognizes that cancer and fertility combine to create a new set of issues to be addressed, such as infertility having a unique impact on individuals because of their cancer diagnosis. Most research on infertility has been on “healthy” individuals and couples. For example, those who are infertile commonly desire to feel “normal” when compared with their peers who can conceive [23]. But for those who have survived cancer, having a child may take on an even greater importance because it allows them to feel not only normal, but healthy as well [8]. Further, cancer may alter the experience of infertility differently for men and women. For example, Clarke et al., who studied otherwise healthy couples, concluded that “Infertility shatters previously held perceptions of the body and the self as healthy, whole, and normal” (p. 110) [23]. For cancer patients, their bodies have already “let them down.” Men with cancer are placed in a unique position compared with men who have infertility issues in that they may be more likely to be targeted for medical treatments or take the “blame” for a couple’s infertility, an experience more akin to those of women in studies of infertility.

1 There are many conceptions of masculinity and femininity available to men and women that may not rely so heavily on fertility and parenthood, but those that are more socially validated tend to be premised on more traditional notions of women as caregivers (including mothers) and men as sexually potent providers (see Clarke et al. 2006).
Moreover, for cancer patients, infertility may interplay with concerns over sexual identity and performance in a unique way from those who are infertile. Clarke et al. found that men’s sense of sexual identity was more compromised than a woman’s because men equated infertility with sexual dysfunction whereas women’s desirability as a sexual partner was not called into question. Depending the form of cancer, issues of sexual dysfunction or desirability may take on a different meaning for those with cancer. Testicular cancer can lead to sexual difficulties in men, so issues of infertility may be even more closely tied to issues of sexual performance and virility. Women, such as those with breast cancer, must contend with infertility in addition to changes in body image related to cancer treatment (such as a mastectomy or hair loss), which can alter their feelings of sexual desirability, and other bodily changes that may alter one’s desire or ability to engage in sexual activity, including hormonal changes and fatigue [24,25]. Those with or who have had cancer must confront possible infertility in a context where one’s entire sexual being has been impacted by having cancer.

Beyond one’s perceived status as a sexual partner, cancer survivors have reported that infertility, or its possibility, can cause tension in relationships, particularly ones viewed as “serious” or “committed” [8,25]. In fact, in looking at testicular cancer, an important determinate of “good health-related quality of life” 3–13 years post-treatment is associated with having intact fertility, having children, and living with a partner (p. 1597 [26], also see [27,28]). Those who are infertile may also be troubled over their ability to maintain or begin a partner relationship, and for cancer patients, this issue is further complicated by their own concerns of reoccurrence and survivorship. Many women who have had cancer are concerned that becoming pregnant will make the reoccurrence of cancer more likely or that their children will be more susceptible to illness.2 Infertility and having children may be markedly distinct experiences for those with or who have survived cancer, which makes parenthood and infertility among cancer survivors an interesting topic for social scientists interested in family studies. It also presents an intriguing gender comparison because of the potential differences in the long-term impact of infertility on the survivorship experiences of men and women.

Race/Ethnicity and Oncofertility

The above discussion highlights the importance of building on the long tradition in gender comparative research to better understand how cancer patients deal with possible infertility, associated health care decisions, and the long-term impact of infertility on their lives. The experience of cancer and fertility, however, may differ along other social statuses as well. An important area of inquiry would be

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2 Despite these common fears among those who have had cancer, there is little scientific evidence. For complete discussion, see fertilehope.org.
comparative analyses looking at the fertility concerns and related health care decisions by race/ethnicity. Research within the social sciences has well-documented inequities across racial and ethnic groups in terms of infant mortality, life expectancy, exposure to health insurance, and the quality of medical care available. This inequity extends to cancer as well. Overall, cancer rates vary by racial and ethnic background. For example, African–American men and women in general have a higher overall incidence of cancer, including higher rates of prostate, cervix, and lung cancers [29]. There are also disparities in when cancer is diagnosed and mortality rates. For example, although Caucasian women have the highest overall incidence rate of breast cancer, they are diagnosed at earlier stages and have lower mortality rates than African–American women [29,30]. These disparities in terms of cancer diagnosis, treatment, and morbidity have been linked to a host of interlocking economic, social, cultural, and environmental factors including health insurance coverage, access to quality health care, and the availability of economic resources, as well as differences in risk-behaviors (e.g., smoking rates), cancer screening behaviors (e.g., mammographies), and underlying risk factors for some cancers (e.g., obesity and history of infectious disease within a group) [29].

Research within oncofertility could build upon this firm foundation of looking at health care inequalities by race/ethnicity and associated differences in socioeconomic status. This area of research is important because whether or not a woman or man takes steps to help maintain fertility functioning (or is made aware of potential options) will impact his or her later ability to bear children. Hence, systematic variation in the options and information accessed by various groups (such as poorer women or racial/ethnic minorities) and their subsequent health care decisions may lead to later disparities in terms of which survivors are able to preserve fertility through the latest and emerging reproductive technologies. Down the road, those who have impaired fertility will also have different access to resources (e.g., financial resources and health insurance) to take advantage of costly fertility treatments (e.g., IVF) in order to conceive and bear biological children. Similarly, those with impaired fertility will differ in their ability to pursue other avenues to become parents, including adoption and surrogacy, due to financial constraints, legal issues (e.g., bans on adoption for single or homosexual women), and cultural or ethical concerns (e.g., cultural proscriptions against surrogacy).

**Race/Ethnicity and Patient–Physician Interactions**

In particular, research should consider racial/ethnic differences in patient–physician communication and their impact on health care decision-making regarding fertility and fertility preservation options. This emphasis will help to uncover possible inequities in terms of cancer patients’ access to information, their ability to pursue fertility preservation treatments, and ultimately, differences in terms of which groups of survivors are able to become parents. Today, racial and ethnic minority groups make up 25% of the United States, but by 2,050 these groups will constitute
the majority of the population [31]. Increasingly, doctor and patient interactions will take place in a setting of cultural dissimilarity, which may influence how information and concerns are shared, how fertility preservation options are considered, and how health care decisions are made [31]. Research would be advised to understand how such sensitive health care decisions regarding fertility are made in the context of racial/ethnic (along with socio-economic) dissimilarity that will continue to become more commonplace. An important part of this research would be to understand how gender further influences the discussion of infertility between cancer patient and doctor. Depending on religious or cultural backgrounds, women and men with cancer may be more willing to share concerns regarding sensitive topics like loss of fertility or sexual performance with a physician when they share a common cultural background or language skills as their doctor.

How doctors approach fertility may differ based on the patient they are advising. For example, research has shown that doctors with different patient populations can vary in how they convey medical information. Doctors with largely minority populations, as compared with those with a Caucasian client base, are less likely to suggest preventative care (e.g., mammographies) and these differences have been attributed to physician education, time spent with patients, and the socioeconomic status of patients [32]. As stated above, doctors may share more fertility-related information with cancer patients when they share a similar status or cultural background.

Examining issues of racial and ethnic variation in doctor–patient relationships and its impact on infertility-cancer related treatment choices is vital because of the varied histories of racial and ethnic groups within the United States health care system, particularly the legacy of distrust for some groups. A patient may distrust the medical system based on their personal experiences with overcrowded or outdated health care facilities (which are undoubtedly linked to economic resources), and also from historical antecedents. Culturally, many racial and ethnic groups may avoid medical treatment because of “deeply embedded distrust of the medical system” [33] stemming from a negative racial or ethnic history with the medical community (e.g., Tuskegee experiments) and perceived cultural insensitivity among doctors [34]. Tense interactions between health care staffs and patient may differ by gender as well. For example, the gendered nature of the traditional doctor (male)–patient (female) relationship has resulted in women’s health being compromised based on the history of forced sterilization for many minority groups [35]. This history may make minority women particularly wary of discussions regarding fertility with physicians, who tend to be Caucasian males.

**Race/Ethnicity and Family and Community Involvement**

While health care decisions are commonly thought of in terms of a patient–physician dyad, exploring the role of family, and even the larger community, will be particularly important for understanding fertility-related concerns and decisions
across racial/ethnic groups. For example, research on African–Americans with cancer has shown a reliance on family as a source of information (along with misinformation) [34]. The role of the larger community in the experience of illness can also differ by race/ethnicity as well as gender. One study found that Japanese–American men and European–American women facing cancer were “able to draw on their social support networks more readily and accept the dependent role more easily” whereas European–American men and Japanese–American women were more distressed in facing cancer (p. 579, [31]). Further, an individual’s fertility treatment decision may be influenced by their family through larger community, cultural, and religious traditions and values. Many treatment options, such as emergency IVF or alternative routes to parenthood, such as surrogacy or adoption, are not seen as acceptable within some cultural or religious groups. Understanding the nature of cultural differences between patient and doctor, the roles of families and communities in health care decisions, and how these impact fertility treatment decisions and concerns is important because of the increasing relevance of post-cancer infertility for many families and the increasing diversity of the United States.

The Digital Divide and Race/Ethnicity

Finally, an increasingly important area of research within oncofertility would be to look at racial/ethnic differences and disparities in terms of access to health care information beyond health care practitioners, including Internet- and Web-based resources. In general, “e-health” refers to information and communication technologies, most notably the Internet, as sources of health-related information for individuals and as mechanisms that can promote health-related behaviors. Although patients still rely heavily on practitioners for health care advice, other sources of health-related information, including e-health Web sites (e.g., cancer information sites and online support groups) have become increasingly important avenues for information related to prevention behaviors, treatment options, and even emotional support [36–38]. Generally, it has been well documented that a “digital divide” exists along socio-economic, education, and racial/ethnic lines with regard to access to the Internet (although this gap has somewhat narrowed from the late 1990s) [36]. Being newer sources of information and intervention, e-health Web sites and programs have not been widely evaluated, but early research shows positive results in the potential of e-health sources to contribute to better health outcomes, including promising findings on shared decision-making and healthy behavioral changes (for overview, see [38]).

In terms of those with cancer, comparative research is needed on differences in access to computers and the World Wide Web, but also on how racial/ethnic groups use online sources (e.g., entertainment or health-related purposes) and the accessibility and relevancy of information on the Web that meets “the cultural, language, or literacy needs of the individual user” [37]. Improved communication technologies
will undoubtedly have consequences for a range of cancer-related issues, including the use of preventative screening procedures (e.g., self-exams for testicular and breast cancer) and healthy lifestyle behaviors (e.g., smoking cessation). Studying access to electronic forms of information is, however, particularly relevant for oncofertility because of the rapidity with which health care decisions regarding fertility preservation need to be made. Procedures often need to occur prior to cancer treatment. The Web may provide a source of not only quick information, but also the most up-to-date information because new and experimental options may not be familiar to all doctors. Also, since doctors do not often prioritize issues of infertility or treatment options when treating patients with cancer, online sources and even support group sites may provide much needed information regarding infertility and treatment options for patients. Looking at access to e-health sources is vital because differences in the availability of e-health information across racial/ethnic and socioeconomic groups may have long-term consequences on cancer survivorship experiences with regard to parenthood and family formation.

Conclusion

The above discussion highlights some of the important issues that need to be addressed within the social sciences and oncofertility. I focused on individual level experiences and decision-making processes because so little is known about the fertility concerns of those with cancer, how they make fertility-conserving treatment choices, and their survivorship experiences regarding parenthood and family planning. An understanding of how these issues may differ by key social status, particularly gender and race/ethnicity (along with socioeconomic status or religious affiliation), is important because of the possibility of disparities in terms of fertility and parenthood for cancer survivors.

As oncofertility as a field of scholarship grows and as its biomedical techniques become mainstreamed into medical practice, there will be ample opportunity for research focusing on meso- and macro-levels of analysis. How do scholars come together and build an interdisciplinary field? How do norms concerning research and scholarship develop when actors come from a variety of fields and backgrounds? Oncofertility social researchers can also examine how emerging technologies become integrated into cancer care. How do hospitals and medical education programs integrate new standards into practice? How are such reforms institutionalized and is there ever resistance to new technologies? Research could also look at how biomedical technology affects the social perception of illness. Cancer is increasingly a survivable condition with most patients returning to the trajectories of their lives, but what is the cultural image of the cancer patient? Will expanding awareness that cancer patients often can and do become parents post-cancer help to change the societal image of cancer from one of a devastating illness to that of a manageable disease? These are just some of the ways that social scientists can expand on the initial scholarship advanced here. The ideas put forth here are just
some important first steps in developing robust scholarship that will draw together scholars from a range of fields to ask new questions and develop new concepts and ways of looking at the important and growing concern of infertility among cancer survivors.

References

5. Lane N. Alarm bells should help us refocus. Science 2006;312:1847.