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UNIVERSITY OF CALIFORNIA, SAN DIEGO

Disruption to the Gendered Body:
How Oncologists and Patients Understand the Cancer Experience

A dissertation submitted in partial satisfaction of the requirements for the degree
Doctor of Philosophy

in

Sociology

by

Laura Elizabeth Rogers

Committee in charge:

Professor Mary Blair-Loy, Chair
Professor John H. Evans
Professor Valerie Hartouni
Professor Kwai Ng
Professor Janet Shim

2018

The Dissertation of Laura Elizabeth Rogers is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

Chair

University of California, San Diego

2018

DEDICATION

This dissertation is dedicated to Cindy.
I want to be you when I grow up.
Your story continues to inspire me.

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VITA

EDUCATION

- 2010 B.S. Sociology, James Madison University: Harrisonburg, VA.
Minors: Women's Studies and Criminal Justice
- 2012 M.A. Sociology, University of California, San Diego
- 2013 C.Phil Sociology, University of California, San Diego
- 2018 Ph.D. Sociology, University of California, San Diego
~Advanced to Candidacy: December 2013
~Field Exams:
* Cultural Sociology (Professor Kwai Ng and Professor Mary Blair-Loy)
* Social Inequalities (Professor Isaac Martin and Professor Akos-Rona-Tas)

RESEARCH INTERESTS

Gender and Sexuality, Cultural Sociology, Inequality and Stratification, Sociology of Bodies and Embodiment, Medical Sociology, Work and Occupations

PUBLICATIONS

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- 2014 Davis, Alexander K., **Rogers, Laura E.**, Bryson, Bethany. "Own It! Constructions of Masculinity and Heterosexuality on Reality Makeover Television." *Cultural Sociology* 8 (3): 258-274
- 2015 **Rogers, Laura E.** "Helping Them Help Themselves': How Volunteers and Employees Maintain a Moral Identity while Sustaining Symbolic Boundaries within a Homeless Shelter." *The Journal of Contemporary Ethnography* 46(2): 230-260.
- 2017 Blair-Loy, Mary, **Rogers, Laura E.**, Daniela Glaser, Y. L. Anne Wong, Danielle Abraham, and Pamela C. Cosman. "Gender in Engineering Departments: Are There Gender Differences in Interruptions of Academic Job Talks?" *Social Sciences* 6(1): 29
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ABSTRACT OF THE DISSERTATION

Disruption to the Gendered Body:
How Oncologists and Patients Understand the Cancer Experience

by

Laura Elizabeth Rogers

Doctor of Philosophy in Sociology

University of California, San Diego, 2018

Professor Mary Blair-Loy, Chair

A common cultural belief is that our body parts and sexual organs inevitably and invariably dictate our gender identities. While sociologists have begun to understand different ways in which individuals alter their body to match their gender identity, previous literature focuses on transgender individuals. Little research has focused on the effects of involuntary changes to the body. I show that although cancer survivors rely on limited, body-centric cultural definitions of masculinity and femininity, the changes to their bodies provide them with an opportunity to alter their definitions of what it means to be a man or a woman.

In this dissertation, I analyze a large yet understudied population. I conducted in-depth

semi-structured interviews with 63 people who had been diagnosed with the four gender-specific cancers—breast, gynecological, prostate, and testicular cancer—and 27 oncologists who treat these diseases. Studying the disruption to the gendered body for cancer patients allows us to better understand the relationship between the cultural definitions of masculinity and femininity, the body, and gender identity.

First, as does the broader public, the women and men in my sample generally define masculinity and femininity through cultural understandings of the body (*i.e.*, they equate femininity with breasts and masculinity with sexual function). Second, undergoing treatment that threatens these cultural definitions allows them to change their understanding of their own gender identity. Third, this process yields different outcomes for women and for men. Women feel empowered and redefine themselves as strong, moving beyond cultural definitions of femininity defined exclusively by appearance. In contrast, men redefine masculinity as broader than sexual function, and they are forced to confront their mortality and the loss of the control that they have taken for granted as men. Last, because doctors also rely on the same narrow definitions of masculinity and femininity, they proactively prescribe biomedical technology to resolve a limited number of side effects and unintentionally ignore others.

CHAPTER 1: INTRODUCTION

People generally perceive their bodies to be their most personal possession; the one thing of their very own that has not been altered by the social world because they have had it since birth. However, the body has recently become a site to study the social. The body is a symbolic asset for men and women to represent their masculinity and femininity. The body is thus an analytical site that helps us better understand sociological qualities and characteristics embodied within individuals, particularly related to gender. Bodies then dictate the cultural expectations for men and women and maintaining the “right” anatomically correct gendered body is vital for “doing” gender appropriately. Gender identities are then created through an individual’s understandings of his/her gendered bodies. While scholars agree that gender identity construction is linked to bodies, little research analyzes what happens to an individual’s gender identity when the body’s gendered appearance and function is disrupted.

This dissertation addresses the following questions. What happens when individuals lose their “right” body? What happens when gendered bodies are unexpectedly altered and changed? How does this problematize or reproduce cultural understandings of gender more broadly?

Cultural expectations of gender become embodied (Cassell 1996; Martin 1998; McNay 1999; Young 1990), leading individuals to connect their bodies with their own gender identity. This dissertation looks at how gender identities are challenged or reproduced when gendered bodies are disrupted. Over time our gender identities become taken-for-granted and this disruption provides an opportunity for individuals to articulate and make sense of their embodied beliefs. The cultural understanding of the “right” gendered body that functions in the appropriate ways shapes how we understand ourselves and our expectations for others. Cancer patients often need extensive surgeries to remove cancerous cells, some of which result in the loss of entire

gendered body parts (breasts, ovaries, testicles) or the loss of function of a gendered body part (impotence, the inability to bear or have children). This damage to the gendered body that cancer patients face opens the door to understand the salience of gender as a social structure. I argue that this disruption to the everyday perceptions of the “gendered self” caused by unexpected body amputation provides us with a unique opportunity to analyze the broader discourse around gender in society, because doctors and patients are forced to confront the relationship between gender and the body head-on.

Gendered bodies are defined by body parts and organs that are often understood by members of society to exist exclusively with one sex and not the other due to their role in reproduction. But bodies are also gendered as specific body parts are sexualized; therefore, the breasts, the vagina, and the penis are also socially significant gendered body parts, aside from their role in reproduction. I think it is important to understand how sex and gender are socially constructed without partitioning sex and sex roles into the realm of the biological. While I distinguish between sex and gender to remain consistent with the literature, I will refer to body parts that are often affiliated with sex as “gendered” body parts, because I believe it is theoretically important to understand how sex is also socially constructed (Laqueur 1990; Oudshoorn 1994).

Understanding the social experience for cancer patients is a socially significant site of investigation. Cancer is the second leading cause of death in the United States behind heart disease (CDC 2017). As such, cancer, particularly gender-specific cancer, has an extraordinary degree of visibility and prominence.² In 2014, there were almost 15 million people living with

² While breast cancer is likely the most visible gender-specific cancer with the pink ribbon movement and advocacy groups like Susan G. Komen, more attention has been brought to gynecologic cancers with Gynecologic Cancer Awareness Month, walks, and teal ribbons and prostate and testicular cancer with “No Shave November.”

cancer in the United States and nearly 40% of men and women will be diagnosed with cancer in their lifetime (ACS 2018).

To understand how cancer treatment affects gender identity, I interviewed oncologists and cancer patients about their understanding of gender and the cancer experience, particularly related to changes of the body. By interviewing cancer patients and survivors, I analyze how they view the loss of (or loss of function of) a gendered body part as well as how their perceptions of their self and identity change when undergoing cancer treatment. I also look at how they understand their role in making decisions about their treatment and how these decisions are shaped by their understandings of broader cultural expectations of masculinity and femininity. By interviewing oncologists, I access the medical discourse surrounding gender and the body as well as gain insight into the role of medical professionals in producing or deconstructing cultural beliefs of masculinity and femininity. Understanding the discourse of medical professionals is particularly important because their position gives them the authority to prescribe solutions to the gendered concerns of their patients.

I interview cancer patients who have been diagnosed with cancers that affect socially significant body parts that are often understood as “gendered:” breast cancer, gynecological cancers, prostate cancer, and testicular cancer, as well as the oncologists who treat these cancers. This dissertation analyzes the constructions of masculinity *and* femininity within a similar context, because gender is a relational *system* and not simply an attribute of individuals (Connell 1995; Moynihan 2002). Therefore, I studied men *and* women with cancer and the understandings of the physicians who work with patients with gendered cancers.³ Understanding how each of

³ Oncologists in specific fields (gynecological oncology, for example) work only with women or men, while oncologists in other fields (radiation oncology or medical oncology) may work with men and women. See Chapter 2 for descriptive information on my sample of oncologists to see the number of oncologists that worked with specific forms of cancer.

these cancers shapes gender identities differently is vital to analyzing how cultural beliefs of gender are tied to different gendered body parts.

This dissertation examines the cultural discourse of gender embodied within individuals and embedded throughout social life in order to better understand the pervasiveness of the gender structure (Martin 2003; Risman 2004). The disruption of the gendered body provides an opportunity to understand the salience of gender as a social structure, as well as, provides a place in which individual actors can challenge or alter perceptions of gender and the body.

This dissertation makes significant contributions to the sociology of gender, gender studies, cultural sociology, and medical sociology. Gender literature has focused a great deal of attention on changing gendered bodies. However, the focus has often been on those who voluntarily undergo treatment with trans- individuals (Schilt and Westbrook 2009; Schrock 2005) or the involuntary treatment of intersex children (Fausto-Sterling 1993; Kessler 1990; Turner 1999). Studying the *involuntary* disruption to the gendered body and the options for subsequent reconstruction in *adults* provides a unique opportunity to study how gender is articulated by individuals who have embodied cultural expectations of masculinity and femininity. This dissertation contributes to the field of cultural sociology as this project provides an opportunity to study how culture is *embodied*—how cultural beliefs become embedded within individuals. Medical sociologists Rosenfeld and Faircloth have recently made a call for research on the medicalization of masculinity, specifically by looking at the “construction and regulation of prostate and testicular cancer” (Rosenfeld and Faircloth 2006:19). This research will begin to answer that call, as well as look at how masculinity and femininity are medicalized simultaneously and relationally. This research also looks at the role of medical professionals *and*

patients in the cancer experience, providing a more holistic view of cancer and its social consequences as compared to research that has focused solely on patients' accounts.

This dissertation answers the following questions: 1) how do cancer patients and oncologists talk about masculinity and femininity in relationship to the cancer experience, particularly in relationship to changes of the body? 2) How are these narratives tied to decisions about reproductive technologies and the reconstruction of bodies? 3) How does the type of cancer or specific treatment shape the ways oncologists and cancer patients discuss broader cultural understandings of cancer and gender? 4) What are the effects on an individual's gender identity when their body is involuntarily altered?

The next section presents my theoretical framework, which draws on the literatures of sociology of gender, gender studies, the sociology of the body, and medical sociology.

Following, I present the chapter organization outlining the goal of each chapter.

THEORETICAL FRAMEWORK

I begin by discussing theories about the social construction of gender and the role of cultural gendered beliefs. I explore how these cultural expectations are shaped by essentialist beliefs about the biological difference between men and women defined in opposition to one another based on the "right" body parts and reproductive organs. I explore how cultural expectations for masculinity are defined against femininity and the importance of studying gender as a *relational system* and not just an attribute of individuals. I then extend theories of gender performativity to understand how these beliefs become *embodied*, not just enacted. I then examine the literature on the role of the medical field in constructing and reproducing understandings of gender and the body and more currently, its role in medicalizing masculinity

and femininity. Lastly, I will discuss the current literature that uses cancer as a site to study gender, as well as articulate what this dissertation does differently.

Gender as a Social Structure

Sociologists, feminists, and queer theorists have written extensively about the social construction of gender, based on the belief in a gender binary consisting of two separate social groups (men/male and women/female) defined against each other (Butler 1990). These gender categories are designated based on specific body parts, behaviors, and personal characteristics of individuals, assuming that men will have certain bodies, behaviors, and roles that are distinctly male, separate and distinct from women's bodies, behaviors, and roles (Butler 1990; Butler 1993). Society uses the differences in male and female bodies and reproductive organs as a classificatory system to create a gender system establishing a clear distinction between the two (Douglas 1970). By looking at gender as a system or social structure, we can understand the role of resources and cultural schemas in producing and reproducing gender within individuals and institutions (Ridgeway and Correll 2004; Risman 2004; Sewell 1992). "The widely held cultural beliefs that define the distinguishing characteristics of men and women and how they are expected to behave clearly are a central component of that system" (Ridgeway and Correll 2004:511). These gender beliefs and schemas, often understood as stereotypes (Eagly et al. 2000), have been most frequently studied by looking at how individuals deploy these beliefs in interaction (Ridgeway and Correll 2004). Ridgeway (2011) notes that the ability to classify another's gender is vital to organizing interaction and one's sense of self. Therefore, gender is a primary category system that systematizes social relations through personal interaction, organizations, and institutions (like family, work, medicine).

Individuals employ gender schemas in interaction or “do” gender (Butler 1990; Fenstermaker and West 2002; West and Zimmerman 1987). Gender performativity is based on Goffman’s theories of interaction, performance, and dramaturgy (Goffman 1959). Men and women draw on these gender beliefs to perform their masculinity or femininity for the approval of others. “It is the ‘appropriate’ kind of performance of all things understood as appropriate for female-bodied (feminine performance) and male-bodied (masculine performance) people” (Crawley et al. 2008:46). These interactions are based on hegemonic beliefs that have become so pervasive that everyone knows what they are and how to perform them (Ridgeway and Correll 2004). Thus, gender operates as a taken-for-granted system of difference based on perceptions of male and female bodies (Garfinkel 1967; Kessler and McKenna 1985; Ridgeway 2011; West and Zimmerman 1987).

An “ideal man” is expected to be aggressive, powerful, sexually domineering, competent, and rational, to name a few characteristics (Connell 1987; Connell 1995; Kimmel 2005). An “ideal woman,” on the other hand, is expected to be passive, weak, warm, and relational/better at communal activities (Connell 1987; Connell 1995; Ridgeway and Correll 2004; Schippers 2007). These characteristics are defined in relationship to one another; masculinity is composed of qualities that are defined in opposition to femininity. Characteristics of masculinity are often complemented by an inferior characteristic attached to femininity (Connell 1995; Schippers 2007).

Hegemonic masculinity characterizes the “culturally idealized form of masculine behavior” (Connell 1987:83). “Many men align with characteristics such as stoicism and sexual prowess, and seek to emulate hegemonic forms of masculinity that are equated with being successful, capable, reliable and in control” (OliFFE 2005:2250). According to Garlick (2010)

being in control is crucial to “being a man.” Therefore, even men who do not meet these qualities will continue to strive for them. In the context of sexual relationships, men are assumed to be sexually aggressive and initiate sexual activity (Burns and Mahalik 2007; Edgar 1997; Kilmartin 2000; Lee and Owens 2002). Therefore, manhood and masculinity are tied to erections and being unable to operate according to these dominant ideals is assumed to be emasculating (Kilmartin 2000; Kimmel 1987; Kimmel 1990; Oliffe 2005).

Because traits like being gentle, compassionate, and weak are associated with women, men learn that they should avoid these traits in order to preserve their masculinity. Men who fail to be strong and self-reliant are punished; similarly, women who fail to express warmth and compassion are chastised (Connell 1987; Cuddy et al. 2008; Hollander 2001; Prentice and Carranza 2002). Therefore, explorations of femininity and masculinity must focus on gender hegemony as a *relational system*. While no man or woman engages all of these respective traits all of the time, most people are aware of the social expectations of who they should be and how they should act. Moreover, these beliefs are embedded *within* individuals and throughout social life—they have become institutionalized (Martin 2003; Ridgeway and Correll 2004; Risman 2004; West and Zimmerman 1987).

Embodied Gender and Gender Identity

Scholars have long understood gender as a performance that is enacted *with* our bodies, as a way of portraying and expressing one’s feminine or masculine self. Yet there are also gendered expectations of the body in its appearance and function. What we do *with* our bodies often reflects masculinity and femininity as well. For example, men who engage in sexual activity with other men are often seen as less masculine or even feminine (Connell 1995; Schippers 2007). We also use our bodies to reflect masculine and feminine ideals (*i.e.*, being

muscular for men or being slim for women). Furthermore, our body parts are always supposed to align with our perceptions of our gender and our masculinity/femininity; men and women should have the appropriate sexual organs and they should function in expected ways. “Gendered expectations produce the very real effect of dichotomizing body knowledge—how we come to know, understand, and use our bodies and how we understand our relationship to each other and the world” (Crawley et al. 2008:3). The expectations to achieve an ideal masculinity or femininity create specific gendered performances based on cultural gendered beliefs, and these performances and beliefs become embodied, recreating the gendered system.

The constant and repetitive performativity of social expectations convinces us that gender is inherent in our bodies, biologically and naturally (Butler 1988; Butler 1990; Crawley et al. 2008). The social, in turn, becomes personal. We create our gendered “self” through these gender performances and begin to embody these cultural beliefs (Martin 1998; Mead 1934; Young 1990). “The body does not precede that understanding [that bodies are understood to be sexed differently], nor does the understanding precede the body... Our understandings of difference shape our behavior, which shapes our bodies, which shape our understandings of difference” (Crawley et al. 2008:40). Our bodies are then different because we internalize and embody difference.

Beyond the visible differences of gendered bodies, we use our bodies to understand our own gendered self. Gender is then, “an embodied ‘logic of practice’... We learn gender before we learn speech. We do gender before we think abstractly” (Cassell 1996:45). The gendered schemas and cultural expectations for men and women are incorporated *into the corporeal* (McNay 1999). Gender schemas are embodied within individuals creating gendered “selves,” which shape how we understand who we are. “The body mediates self-identity and social

identity: consequently, the social meanings attached to bodily display and expression are an extremely important factor in an individual's sense of self, and his or her feelings of inner worth" (Shilling 1993:82-3). Therefore, the disruption to the gendered body as a consequence of cancer treatment provides a unique opportunity to study gender identity and cultural schemas of gender. Changes to the gendered body force individuals to articulate perceptions of their own self-identity.

Medicine's Role in Reproducing the "Naturalness" of Gender

Gender is defined as two distinct and oppositional groups—men and women—believed to have essential behavioral and social qualities that are inherent to them. These beliefs are legitimated by the cultural repertoires positing gender as two *biologically* distinct groups (Lorber 1994; Ridgeway 2011; Ridgeway and Correll 2004). "In Western societies, the accepted cultural perspective on gender views women and men as naturally and unequivocally defined categories of being (Garfinkel 1967:116-18) with distinctive psychological and behavioral propensities that can be predicted from their reproductive functions" (West and Zimmerman 1987:127). These beliefs have become normalized and justified through scientific and medical discovery. In the eighteenth and nineteenth centuries, science became the legitimate source of authority in defining the natural world. As such, the medical field replaced the church as a key normalizing institution (Foucault 1978; Laqueur 1986; Laqueur 1990).⁴

Biomedicine is one of the most important institutions in normalizing gender, particularly because of its authority over bodies (Hancock et al. 2000). The medical institution is often

⁴ Normalization is created through knowledge-production surrounding the proliferation of perversions or aberrant practices. It is an abstract process in which people are not explicitly *taught* an idea through specific organizations or institutions; the social project now is to be normal. Normalization is often defined in contrast to what is defined as "abnormal." More and more things are defined as abnormal, creating a smaller and more acute definition of normalcy (Porter 1987). Normalization is created through discipline, knowledge-production, and regularization.

thought to have authority over the body, particularly in its ability to separate the body from the mind. As the medical institution is granted the authority to fix and cure bodies and body parts, it is also given the power to define normality. In defining what is normal, natural, and biological, biomedicine inherently defines and stigmatizes abnormal, unnatural, and unbiological groups by focusing on *difference* (Conrad 1992; Conrad and Schneider 1980). “The term ‘difference’ is used to refer on the one hand to attributes and traits that sit outside a statistical ‘normal’ taken from population averages, and on the other hand, to attributes or qualities that sit outside the range of what is considered acceptable and good or ‘normative’ within a given cultural context” (Malacrida 2004:63). As such, the medical field became invested in discovering the true nature of the sexes and was influential in creating a socially constructed gendered body. Kempner (2006) argues, “Biomedicine and the production of medical knowledge is a primary force in the gendering of the body, especially because biomedicine has the social and cultural authority to define naturalness and normality” (Kempner 2006:635).

Similarly, Laqueur (1986, 1990) argues that the “political, economic, and cultural transformations of the eighteenth century created the context in which the articulation of radical difference between the sexes became culturally imperative” (Laqueur 1986:35). He shows how the construction of the sexed body lies in ideological bases and was justified through the increasing rationality of science (Laqueur 1990). Scientists and doctors, almost exclusively men, focused on explaining female inferiority using scientific explanations that reinforced normative understandings of men’s and women’s social bodies. Laqueur (1990) and Schiebinger (1986) explain how the sexed body was defined based on scientists’ cultural understandings of gender. Oudshoorn (1994) extends their theory to describe how even sex hormones were socially constructed, yet defined as natural by the medical field. These authors explore the medical fields

role in reproducing normative understandings of men and women's bodies. Not only has the medicine's authority been used to define the sexes, but it has also been responsible for the reconstruction of actual bodies to fit those ideals.

Given their role in defining what is natural, medical professionals were given the authority to regulate bodies and legitimize the gender structure. "The medical commitment to healing, when coupled with modernity's faith in technology and interventions that control outcomes, has increasingly shifted toward an aggressive intent to fix, regulate, or eradicate ostensibly deviant bodies" (Garland-Thomson 2002:14). Doctors reproduce the gender binary by normalizing male/female sex categories by surgically manipulating the genitalia of infants with ambiguous genitals and by placing a strong emphasis on the need to surgically normalize intersexed people (Dreger 2004; Fausto-Sterling 1993; Fausto-Sterling 2000; Garland-Thomson 2002; Kessler 1990). The medical institution has been critiqued for reproducing and normalizing bodies through the surgical manipulation of genitalia and other types of bodies deemed "abnormal."

Most of the literature on the manipulation of genital organs focuses on intersex individuals and the surgical techniques used to alter ambiguous genitals. Anne Fausto-Sterling (1993) writes about the social importance of having the "right" body parts within the context of intersex children who are born with ambiguous gender identities. She shows how individuals who are born without matching anatomy and gender identity negotiate this incongruence, particularly when their parents and doctors "chose" a specific gender for them based on the size of their external genitalia (Fausto-Sterling 1993). Kessler (1990) interviewed doctors who worked with intersex babies to understand how doctors frame these experiences. She argues that rather than looking at chromosomes and attempting to discover the "true" sex, doctors attempt to

find the “best” sex, most often based on social understandings of an acceptable penis size, necessary for a successful sex life.

Fausto-Sterling and Kessler were among the first scholars to discuss the medical fields’ role in manipulating gendered bodies and the subsequent consequences on gender identity; however, they do not address how individuals with seemingly “normal bodies” navigate their social world when they lose a gendered body part. Obviously, a man that has to have his testicle removed is not intersex or trans. Yet the anatomical ambiguity is comparable when looking at how the medical field polices gender boundaries and provides a unique opportunity to look at how *adults* understand the disruption to their gender body.

Not only has the medical field been implicated in constructing ideas about two oppositional biological sexes, but more recently scholars have looked at how gender issues have become medicalized. “Medicalization describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (Conrad 1992:209).⁵ Scholars have engaged in numerous empirical studies that demonstrate how medicalization constructs and reproduces gendered differences. Feminist scholars have looked at the medicalization of femininity through PMS and childbirth (Riessman 1998), female sexual dysfunction (Fishman 2004), menopause (Bell 1987; Kaufert 1982) and cosmetic surgery (Dull and West 1991). Until recently, literature on the medicalization of the gendered body focused primarily on women. However, researchers have begun to focus on the medicalization of masculinity, primarily with regards to impotence and erectile dysfunction. Tiefer (1994) argues that the medicalization of male sexuality produces a universal phallogentric definition of sex that

⁵ “The term *medicalization* refers to two interrelated processes. First, certain behaviors or conditions are given medical meaning—that is, defined in terms of health and illness. Second, medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant for the purpose of securing adherence to social norms” (Riessman 1998:47).

perpetuates women's sexual subordination. Loe (2001) researches how Viagra, one of the first biotechnological drugs⁶ used to "fix" masculinity issues, is used to reproduce men's heterosexual confidence and power. Weinke (2005) studies the increasing emphasis on the medicalization of male performance problems through the production and marketing of Viagra, Cialis, and Levitra; all used to reconstruct the sexually functional male body. However, little research has focused on the medicalization and regulation of male cancers (*e.g.*, testicular and prostate cancer) (Rosenfeld and Faircloth 2006), especially in comparison to the medicalization and regulation of cancers that affect women.⁷

Cancer as a Site

There are four prevalent forms of cancer that are gender-specific, defined as such because they affect body parts that are often understood to exist exclusively with one sex and not the other:⁸ breast cancer, gynecological cancers, testicular cancer, and prostate cancer. An interdisciplinary literature on cancer, primarily written by nurses, oncologists, and psychologists has begun to look at how social and psychological aspects of the cancer experience shape health outcomes and patients experiences. This literature provides important clinical data on the impact of breast, gynecological, and urological cancer treatments on patients' wellbeing. However, this literature is often unreflexive about the social construction of sex and gender and is missing a

⁶ Scholars have recently begun to extend theories of medicalization to account for the increasing reliance of the medical field on technoscientific innovations. Clarke et al. (2003) refer to this process as *biomedicalization*: "the increasingly complex, multisited, multidirectional processes of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine" (Clarke et al. 2003:162)

⁷ With the shift from paternalism to evidence-based medicine (Bensing 2000; Denny 1999; Goldenberg 2006; Mykhalovskiy and Weir 2004; Sackett et al. 1996; Timmermans and Angell 2001; Timmermans and Berg 2003; Williams 2004) one might assume that individual doctors would lose their authority. However, Denny (1999) argues that "it actually reinforces such authority by regulating the conditions under which a physician may speak authoritatively about health and illness" (Denny 1999:247). This medical authority is necessary for the medicalization of social problems.

⁸ While men and women can develop breast cancer, women's breasts have been highly sexualized in American culture and societal beauty standards require that women have appropriately shaped and sized breasts (Dull and West 1991; Ferguson 2000). Additionally, breast cancer is often defined socially as woman's problem, particularly with the rise of the Pink Ribbon Movement (Langellier and Sullivan 1998).

broader sociological analysis of relational gender. Some of these studies begin to look at gender identity but these insights are often limited by an individual level of analysis that disregards cultural schemas of gender relationally and frequently ignores testicular and gynecological cancers entirely. While another strand of this literature begins to sketch out a gender-relational approach to the study of gender and the body (Manderson 1999; Moynihan 2002), researchers have yet to study all four of the prevalent gendered cancers as comparable groups and look at the role of oncologists in the cancer experience.

Interdisciplinary literature has begun to look at masculinity and femininity as psychosocial aspects of cancer and how it affects health outcomes. However, most of this literature focuses on the connection between masculinity and femininity and help-seeking and “adjustment.”⁹

A newer thread of literature has begun to look at the role of socially constructed gender norms in relationship to cancer patients. This research has focused predominantly on breast cancer (Moynihan 2002) and increasingly on prostate cancer, however, very little research has focused on men with testicular cancer and women with gynecological cancers. Gurevich et al. (2004) discuss how men with testicular cancer assert and disavow the link between their physical anatomy and their masculinity. They argue that testicular cancer survivors were able to maintain

⁹ Adjustment is often defined by how patients psychologically adjust after diagnosis and throughout treatment (Fergus et al. 2002; Mathieson and Stam 1995; Taylor et al. 1984). While these scholars have looked at the adjustment of prostate cancer and breast cancer patients in relationship to their masculinity and femininity, these studies often focus on the psychological problems of patients, like depression and self-confidence (Bloom et al. 1987; Cella et al. 1989; Llorente et al. 2005; Maguire 1990; Meyerowitz 1980; Munstedt et al. 1997).⁹ Health outcomes are also studied by looking at how help-seeking. The help-seeking literature looks at how perceptions of masculinity and femininity affect the likelihood of men and women to seek medical care and ask for support. In general, they find that women are more inclined to seek medical and emotional support (Courtenay 2000; Kandrack et al. 1991; Lonquist et al. 1992; Mechanic and Cleary 1980). These scholars argue that gender-role socialization has constructed ideas of masculinity that prevent men from seeking medical care and has potential negative consequences for their health outcomes (*i.e.*, higher rates of mortality) (Broom 2004; Courtenay 2000; Kiss and Meryn 2001; Krizek et al. 1999; Mahalik et al. 2007; Nicholas 2000). This interdisciplinary literature provides great insights into how perceptions of masculinity and femininity shape health outcomes and the potential consequences of different help-seeking between men and women. However, this literature is often unreflexive about the social construction of gender and lacks a sociological analysis of the cultural schemas around gender and the body.

their masculinity by hiding the site of their cancer from others but also felt emasculated due to fractures in their sexuality and fertility. However, Gordon (1995) finds that testicular cancer patients often redefine their experience in a way that reaffirms rather than challenges perceptions of masculinity. None of the men in his sample reported feeling less masculine because they were able to redefine their self-identity.

Little research has focused on gynecological cancer patients, particularly in relationship to their gender identity. Rasmusson and Thome (2008) discuss women's desire for more information about the impact of gynecological cancers on their sexual function. They argue that women's femininity is negatively affected physically and psychologically due to the uncertainty and lack of knowledge about their bodies. They suggest that oncology nurses and doctors should be more proactive in discussing the sexual side effects with women and their partners. Elson (2002) interviewed 40 premenopausal women who had a hysterectomy. She finds that although menstruation is connected to women's gender identity that the loss of menstruation was a relief and did not leave women feeling remorseful. These studies contribute to our understanding of femininity and gender bodies, especially in connection with gynecological cancer patients yet their narrow focus (exclusively studying women's wishes about knowledge related to sexuality and women's perception of their femininity in relationship to the loss of menstruation) leaves a lot of unanswered questions.

Unlike gynecological cancer, there are hundreds of studies analyzing breast cancer. A substantial amount of the literature on breast cancer and the experience of breast cancer patients are told by women themselves in biographical accounts.¹⁰ Audre Lorde (1980), one of the first to write openly about the experience of women with breast cancer, wrote *The Cancer Journals* to

¹⁰ Most other studies on women's experiences with breast cancer focus on moods, attitudes, and coping in quantitative studies by health professionals (Rosenbaum and Roos 2000:156)—see footnote 7.

criticize the oppressive nature of societal views on breast cancer. Lorde's book was one of the first biographies by a lesbian of color and was a revolutionary work in breaking the silence around breast cancer.

In addition to the many biographical accounts,¹¹ Rosenbaum and Roos (2000) look at how a number of women with breast cancer deal with the pervasive cultural meanings of their illness. They argue that breast cancer is often defined in three ways: "(1) breast cancer as equated with death or, alternatively, as manageable and survivable; (2) treatment for breast cancer as compromising to a woman's identity, femininity, and self-worth; and (3) breast cancer as an experience that should not be openly discussed" (Rosenbaum and Roos 2000:153). Rosenbaum and Roos (2000) are among a large groups of scholars that focus on the ways that breast cancer damages women's bodies and subsequently their identities and self-worth. Potts (2000) and Ericksen (2008) also find that breast cancer damages women's self-identity. Ericksen's interview study (emerging from her own experience of breast cancer) notes that most women with breast cancer view the "disease as an attack on her identity as a woman" (2008, 159). For these scholars, the centrality of the breast in defining femininity leaves women feeling "deformed." As a consequence, it is assumed that women's identities can only be restored through reconstruction and other feminine bodily practices.

More recently, scholars have begun to look at the experiences of men with prostate cancer because prostate cancer is seen as the preeminent disease that attacks masculinity. Gray et al. (2000); Gray et al. (2002) find that men with prostate cancer are uncomfortable asking for support because it does not match their perceptions of ideal masculinity. Similarly, Chapple and Ziebland (2002) find that men with prostate cancer are reluctant to consult doctors about their

¹¹ Klawiter (2004) also looks at breast cancer patients' experiences, particularly related to how the shift in disease regimes shapes the experiences of patients undergoing breast cancer treatment. She argues that the shift away from paternalism has allowed women with breast cancer to be more actively involved in the decision-making process.

symptoms because men are not supposed to show weakness. However, O'Brien et al. (2005) find that sometimes men felt that help-seeking was a necessary means to preserve or restore masculinity, as opposed to challenging their masculinity. Aside from masculinity's role in preventing men with prostate cancer from seeking help, research has also focused on how prostate cancer affects men's masculinity. Burns and Mahalik (2007) identify three masculine gender scripts that may contribute to men's adjustment (or issues adjusting) following prostate cancer: self-reliance, emotional control, and sexual potency. Arrington (2008) argues that men in prostate cancer support groups perpetuate society's definition of masculine sexual identity, even if they do not meet that ideal. The men in Arrington's study "defined masculine sexuality solely in terms of the ability and willingness to perform penile vaginal intercourse" (p. 304) and he calls for an examination of the social construction of sex so that society can have a more transcendent view of sexual identity. Gray et al. (2002) analyze the narratives of three men with prostate cancer and argue that while these men renegotiate their masculine identities, the changes occurred within the parameters of performance consistent with hegemonic masculinity. So rather than challenge normative gender expectations, they adapted within them. They defined masculine identity more broadly through work, relationships with women, sexuality, relationships with other men, illness/wellness, and age. The literature on prostate cancer presumes a fixed relationship between sex and masculinity and assumes that impotence necessarily and inherently impacts men's masculine identity [even though many studies have shown that erectile dysfunction is not a serious threat to all men (Cameron and Bernardes 1998; Chapple and Ziebland 2002; Gray et al. 2002; Oliffe 2005)]. Additionally, Oliffe (2005) finds that men were willing to trade impotence for life yet these men had varying difficulties coping with their impotence.

While a lot of research has provided insights into the experiences of men and women with breast and prostate cancer in relationship to their understandings of masculinity and femininity, this literature fails to look at gender as a relational system and compare the experiences of men and women. Additionally, this thread of research often ignores other comparable groups like testicular cancer and gynecological cancers that also affect gendered body parts.

Moynihan (2002) and Kiss and Meryn (2001) have made calls for researchers to focus on the experiences of men *and* women, as most only investigate individuals with a single form of cancer. “A ‘gender relational’ approach to cancer care underpins the ways in which people enter into a set of socially constructed relationships produced and reproduced through actions with each other and in institutions but never in a vacuum” (Moynihan 2002:166). By interviewing men and women with gendered cancers, and by talking to the men and women who treat them, this dissertation will look at the how masculinity *and* femininity are constructed within the same medical context, allowing me to look at the similarities and differences within and between men and women with cancer. This approach has been utilized by Manderson (1999) who undertook a study of how men and women cope with changes to their bodies.

Manderson (1999) examines at how men and women cope after major surgery from a range of serious conditions (including but not limited to cancer). Her empirical project is focused on how individuals recover a sense of normalcy after a traumatic surgery, although she does note gender differences. She finds that, “Consistent with contemporary constructions of femininity and masculinity, women emphasized *the embodiment of femininity*, while men emphasized *the enactment of masculinity*. Thus men’s view of masculinity is tied to activity, linked to work and other kinds of physical tasks. Women, in contrast, hold a passive notion of femininity”

(Manderson 1999:391). However, Manderson does not interview men with testicular cancer or prostate cancer and argues that for someone to make a comparison between men and women's perceptions of their corporeal body that is imperative. She attempts a gender relational approach but does not have groups that are directly comparable because her respondents have a variety of conditions. This dissertation answers that call by analyzing gynecological, breast, testicular, and prostate cancer patients, as well as the oncologists who treat them, and will begin to fill the void in the literature by engaging in a relational approach to gender by studying the experiences of patients with gender-specific cancers. This dissertation is better suited to analyze how the gender structure is embedded within bodies and identities because it compares the experiences of men and women. I ask men and women the same questions about the changes to their bodies and their sense of self and am able to directly compare how changes to function and appearance shape men's and women's masculinity and femininity.

CHAPTER ORGANIZATION

Chapter Two outlines the research design and method used. In order to analyze the cultural discourse surrounding gender identities and the body, I interviewed men and women with comparable gender-specific cancers: breast, gynecological, testicular, and prostate cancer. I also interviewed oncologists that treat these diseases. Chapter 2 outlines how the data was collected and analyzed. I start by discussing the 27 interviews that were conducted with oncologists. Second, I review how the 63 interviews with patients were collected and analyzed. Third, this chapter examines the four cancers in great detail, explaining the prevalence, survival rates, treatment options, and potential side effects. Lastly, I discuss the limitations to this data.

Chapter Three, "Cultural Definitions of Masculinity and Femininity," examines how oncologists and survivors conflate masculinity with sexual function and femininity with

appearance. When discussing concerns about gender oncologists immediately jump to discussions of sex and breasts. I argue that their immediate connection to sex or physical appearance reveals their taken-for-granted and extremely narrow understandings of what it means to be a man or a woman with a gender-specific cancer. While survivors make the same implicit assumptions about the definitions of masculinity and femininity as their doctors, many claim that their own gender identity is still secure and not damaged as the oncologists presume. Their ability to feel secure in their identity even with these bodily changes allows survivors to disconnect their gender identity from their body.

In Chapter Four, “Masculinity, Femininity, and the Role of Relationships,” I explore the role of relationships in explaining why some men and women feel more secure about the changes to their gendered bodies than others. I argue that marriage plays a large part in explaining this difference, for committed partners allow individuals to feel comfortable with their gender identity despite having a body that no longer matches the norm. This disconnect between body and gender identity allows both men and women to disavow patriarchal beliefs about gender and the body and challenge the gender structure. This is particularly surprising given that many gender scholars highlight the role of marriage as an institution in maintaining and reproducing gender essentialist beliefs and unequal power structures for women.

As gender identities become disconnected from bodies as shown in Chapters Three and Four, Chapter Five, “Self, Gender Identity, and Control,” examines the subsequent changes to cancer survivors’ sense of self. Rather than feeling damaged, women continuously noted that their cancer experience helped them realize their strength. They identify their strength as physical strength, emotional and mental strength, and a newfound ability to advocate for and prioritize themselves. Women’s femininity shifts from feelings of insecurity and an emphasis on

the male gaze to that of empowerment and control. On the other hand, men expressed feeling mortal, vulnerable, and out of control. I argue that cancer damages men's sense of self-identity as it challenges men's taken-for-granted control and power.

Chapter Six, "The Role of Biomedical Technology," highlights how cultural definitions of masculinity and femininity shape the ways that doctors prescribe specific biomedical technologies to treat patients' side effects. Given that masculinity is defined by sexual function, oncologists proactively prescribe Cialis and Viagra to alleviate men's concerns about impotence. Similarly, the conflation of femininity with appearance leads doctors to offer breast cancer patients plenty of education and support on the topic of reconstructive surgery. However, these narrow conceptions of masculinity and femininity unintentionally leave men and women with other concerns besides sex and appearance, respectively, without answers and support.

In the Conclusion, I summarize my findings and emphasize the importance of my relational approach. I also highlight the social implications of this dissertation and make specific suggestions to healthcare practitioners and patients dealing with these four cancers. Throughout, I argue that men's and women's experiences and their medical care are shaped by societal beliefs about what it means to be a man and a woman. The involuntary disruption to the gendered body as a consequence of cancer provides an opportunity to analyze how these understandings about gender both influence biomedicine's role in regulating bodies and become challenged by the patients fighting these cancers.

CHAPTER 2: RESEARCH DESIGN AND METHOD

To understand how cancer treatment challenges or reproduces cultural scripts of gender, I interviewed oncologists and cancer patients about their understandings of gender and the cancer experience, particularly related to changes of the body. By interviewing cancer survivors, I analyze how they understand the loss of (or loss of function of) a gendered body part and how their perceptions of self and identity change when undergoing cancer treatment. By interviewing oncologists, I gain access to the medical discourse surrounding gender and the body, as well as, gain insight into the role of medical professionals in producing or deconstructing cultural beliefs of masculinity and femininity. Understanding the discourse of medical professionals is particularly important, because their position gives them the authority to prescribe solutions to the gendered concerns of their patients allowing me to study the medicalization of gender and the body.

DATA

I conducted 90 interviews total: 27 interviews with oncologists and 63 interviews with patients. Interviews were conducted with testicular, prostate, breast, and gynecological cancer survivors. The doctors were oncologists who specialized in treating these four cancers. Breast, gynecological, prostate and testicular cancers represent the most prevalent cancers that affect gendered bodies. Breast cancer and testicular cancer both result in changes to the physical appearance of the body. Both prostate cancer and gynecological cancer result in changes to the function of the gendered body. Certain body parts are “sexed” because of their social significance in relationship to men’s and women’s roles in reproduction; therefore, the ovaries, uterus, cervix, testicles, and prostate are gendered body parts. But bodies are also gendered as specific body parts are sexualized; therefore, the breasts, the vagina, and the penis are also

socially significant gendered body parts, aside from their role in reproduction. I think it is important to understand how sex and gender are socially constructed without partitioning sex and sex roles into the realm of the biological.

Nearly 40% of people will be diagnosed with cancer in their lifetime (ACS 2018). Prostate cancer and breast cancer are the most prevalent forms of cancer for men and women, occupying 20% and 30% of all cancer cases for men and women respectively (ACS 2018). The number of individuals living with, being treated for, or in remission from some form of gendered cancer is substantial—over 15.5 million Americans have or have had cancer as of 2016 and over 1.7 million people are expected to be diagnosed with cancer this year alone (ACS 2018).

Interviews with Oncologists

In 2012, I conducted in-depth semi-structured interviews with 27 doctors who work with breast, gynecological, and urological cancer patients. All of the oncologists interviewed were affiliated with a large nationally ranked research-university's cancer center. While I do not claim to be able to make generalizable claims about the practices of all oncologists, there is no evidence suggesting that the medical practitioners at this institution are unusual in how they treat their patients.¹² Additionally, the doctors I spoke with were trained at and have worked in a number of different hospitals across the United States, which indicates that I may be tapping into a broader professional discourse. Further, since these physicians work at a research and teaching hospital, they must stay up to date on medical literature, train fellows and medical students, and participate in cutting-edge research for funding and clinical trials. The fact that these individuals worked within a teaching university may have made them more open to talking to a researcher. However, their interactions with patients should not be different from oncologists at other

¹² Additionally, with the rise of evidence-based medicine, doctors have begun to streamline and standardize the care of patients (Denny 1999; Sackett et al. 1996; Timmermans and Angell 2001; Timmermans and Berg 2003).

institutions or hospitals. All of the doctors within the study work in the same organizational structure, so all have access to the same administration, staff support, patient community, and other organizational resources. Additionally, these oncologists see a significant number of patients. This cancer center is one of the largest cancer centers and ranks in the top 25 best cancer centers in the United States. While patients have the option to be treated in a number of different hospitals and hospital settings in the area, this cancer center is well known for its patient care, clinical trials, and ability to treat those with and without insurance.

I contacted every oncologist who worked with gynecological, urological, and breast cancers in this institution. I had a response rate of approximately 80 percent. Interviews ranged from 45-75 minutes (averaging an hour a piece), and all but two were conducted in the participant's office (one was at a local Starbucks and one was in the interviewee's home). I recorded 26 of the 27 interviews, and I took meticulous notes during the unrecorded interview. Eleven of the interviews were with oncologists who are women, and 16 were with men. In order to protect the anonymity of my respondents and the medical center, I intentionally do not include information about the number of men and women within each subspecialty. Seven of the respondents were medical oncologists (who deliver chemotherapy), seven of the respondents were radiation oncologists (who deliver radiation), six were surgeons, and five were gynecological oncologists (see Table 2.1).

Gynecological oncologists are responsible for performing the surgery and administering chemotherapy for all gynecological cancers; these doctors work exclusively with women. They are the only specialty that performs more than one type of treatment. A trained surgeon does not also perform radiation. Medical oncologists deliver chemotherapy—some may specialize in specific cancers and other medical oncologists deliver chemo to a variety of cancers. So a

medical oncologist may treat breast cancer patients with chemotherapy and also treat testicular cancer patients with chemotherapy. Urologists can specialize as a urological surgeon or a urological oncologist. Urologists treat diseases of the male and female urinary-tract system and the male reproductive organs. The urologists in my sample work primarily with prostate and testicular cancer patients. Medical oncologists and radiation oncologists generally treat a limited number of cancers, but they are more likely to work with both male and female patients. I draw on all 27 of these interviews in this dissertation.

Table 2.1: Basic Descriptives of Oncologist Respondents

<i>Gender</i>		<i>Type of Treatment</i>		<i>Type of Patients</i>	
Men	16	Radiation Oncologist	7	Breast Cancer	12
Women	11	Medical Oncologist	7	Gynecological Cancer	8
		Surgeon	6	Urological Cancer	12
		Gynecological Oncologist	5		
		Other	2		

The semi-structured interviews illuminate the ways in which doctors say they interact with patients and the types of discussions that they have with their patients. I asked each oncologist open-ended questions about their role working with cancer patients, specifically about how they break the news to someone that they have cancer, how they help someone decide on a course of treatment, and the advice that they give patients about particular issues. I began each interview by asking the oncologists questions about their jobs, what they do on a day-to-day basis, how they were trained, and what they feel are the most important aspects of doctor-patient interaction. I tried to get a glimpse of what they might say to patients by asking them to provide examples of the advice they give. I inquired about the advice they give newly diagnosed patients, and I continued to ask similar questions to discern how they address particular concerns raised by patients. Later in the interview, I asked about patients' apprehensions about each treatment

and the side effects. This was usually the point when oncologists mentioned their patients' fears related to gender. I then probed about the advice that they give their patients for these concerns.

All respondents were given a pseudonym to protect their anonymity. I replaced the last names of the oncologists with the last name of a friend. Given that medical professionals are generally referred to by their last name, I focused on changing their last names to a name that was entirely random.

Interviewing 27 oncologists provided me with insights into how oncologists understand their interactions with patients. While I cannot speak to the actual exchanges between oncologists and patients, I am able to discuss the ways that oncologists understand their conversations with patients and what they say about those interactions.

Interviews with Patients

To study how cancer patients understand their gendered body experiences during or after their cancer treatment, I conducted in-depth semi-structured interviews with the patients themselves. I started interviewing survivors in September 2013. The majority of the interviews were conducted in 2014 but continued into the first half of 2015. I asked them open-ended questions about their experiences with diagnosis, treatment, and recovery, relying on their "illness narratives." Frank (1995) asserts that patients find a voice by sharing their stories of their illness, and medical sociologists emphasize the value of analyzing the illness experience through patients' "illness narratives" (Bury 1982; Frank 1991; Kleinman 1988; Langellier and Sullivan 1998; Mathieson and Stam 1995; Mattingly 1998). Allowing respondents the opportunity to talk freely about their experiences provides them with a space to discuss how their illness shaped their perceptions of their self and their social life (Charmaz 1991; Frank 1991; Kellehear 1990; Langellier and Sullivan 1998; Mattingly 1998). After asking for a narrative of their illness, I

asked more focused questions about side effects, the support that they sought throughout treatment, and how this experience has altered their sense of self, plans for the future, and understandings of their masculinity and femininity. All respondents were asked similar questions in a similar order, but the exact wording of each question and the order varied depending on the flow of the individual interview.

I completed 63 interviews with cancer survivors: 17 interviews with breast cancer patients, 15 interviews with gynecological cancer patients, 14 interviews with testicular cancer patients, and 17 interviews with prostate cancer patients. Throughout the dissertation, I will refer to these individuals as survivors. It is important to me to note and it was important to many of the people that I interviewed that they be seen as survivors from the day that they are diagnosed, not the day that they are labeled cancer-free. While not all of my respondents personally identified as a survivor, it was important to many of them to identify as a survivor from the day of their diagnosis because from that point they were surviving. This was especially true for people with recurrent cancer.¹³

Participants ranged in age from 23-82 because of wide range in ages of diagnosis for each type of cancer. The average age for a testicular cancer diagnosis is 33, while the average age of a prostate cancer diagnosis is 66. Breast cancer can occur at a large range of ages, and the majority of ovarian cancer cases occur in women over the age of 65. The average age range of my participants matches the age range for each form of cancer. Refer to Table 2.3 for descriptive information on the patient interview data. Respondents were also at varying stages of recovery—some individuals had been in remission for more than five years, while, at the other end of the spectrum, some patients were still undergoing treatment. I made sure that there were respondents

¹³ I think it is especially important to refer to these individuals as survivors to honor the memory of the people I interviewed who struggled through difficult treatments and may have since deceased.

within each cancer type with similar lengths of time since diagnosis.

Recruitment

I recruited respondents through a variety of methods; however, most interviewees were recruited from support groups and through snowball sampling. In some cases, I attended the support group meeting and handed out my recruitment information and introduced myself. In other cases, my recruitment flyer was emailed to the support group listserv. All respondents were asked to contact me directly if they were interested in participating, and I did not directly contact respondents without their consent.

Given the rarity of testicular cancer, I was unable to recruit enough testicular cancer survivors in San Diego. Only one testicular cancer survivor was interviewed in person in San Diego. To find additional respondents, I accessed an online support group for testicular cancer patients. The leader of this support group emailed out my recruitment information, and testicular cancer survivors contacted me directly.

Additionally, I registered as a researcher through UCSD's ResearchMatch, which is a national registry of volunteers who would like to learn about research studies (CTRI 2013). I recruited five breast cancer patients and one testicular cancer patient through ResearchMatch.

Table 2.2: Numbers of Patient Respondents Recruited through Various Methods

Recruitment Method	Number of Respondents
ResearchMatch	6
Support Group	30
Snowball	9
Online Support Group	13
Group, not support related	5
	63

Table 2.3: Basic Descriptives of Patient Respondents

	N	Age of Respondent			Years Since Diagnosis				Length of the Interview		
		Min	Max	Mean	Min	Max	Mean	Median	Min	Max	Mean
Breast	17	42	82	61	1	16	4.5	3	50	217	95
Gynecological	15	44	81	62	1	18	5.67	4	45	158	103
Prostate	17	68	81	71	0	15	4.73	3	58	131	91
Testicular	14	23	45	36	1	18	3.64	2.5	58	133	78
Total	63	23	82	58	0	18	4.65	3	45	217	91.5

Interviews

My interviews with patients ranged from approximately one hour to three and a half hours long and averaged 90 minutes. Interviews were conducted at the time and place most convenient for the interviewee, and all but two interviews was recorded. Due to recruitment methods, 13 of my 14 interviews with testicular cancer survivors were over the phone. I also interviewed one prostate cancer patient over the phone. Of the in-person interviews, a large number (39%) occurred in the respondents’ home. I interviewed the rest of the respondents in public places such as coffee shops, restaurants, and libraries, and offices—either my office or theirs. All in-person interviews were conducted in San Diego county. Respondents from phone interviews lived in a variety of different states: Texas, Ohio, New York, Florida, Virginia, Kentucky, and Oklahoma.

Table 2.4: Location of Patient Interviews

Location	
Coffee shop	16
Home	19
Cancer Center	4
Library	2
My office	6
Phone	14
Work	2

Each of the cancer survivors I interviewed was given a pseudonym to protect their confidentiality and anonymity. Pseudonyms were assigned using Social Security Administration data on the most prevalent names in each given generation.¹⁴ Therefore, respondents who were in their late 60s at the time of the interview were assigned a pseudonym from the Social Security Administration’s list of common names in the 1950s. Names were assigned in a random order and once a popular name from the SSA was used, it was not used again. I also did my best not to use common names of actual respondents.

I completed coding through a reciprocal and iterative process of deduction and induction—deductive codes based on theoretical interests and inductive codes that emerged from patterns within the data. Initial coding categories emerged directly from the interview guides¹⁵ and served as a straightforward way to sort the data. I added inductive codes as each transcript was analyzed. For example, when oncologists talked about the necessity to create trust and meaningful relationships with their patients, I inductively coded this as “doctor-patient relationship.” Codes were then collapsed into categories (*i.e.*, codes on how communication with patients was the most important aspect of the doctor-patient interaction and codes about how patients should be actively involved in making decisions were also coded as “patient-centered medicine”). Similarly, discussions about patients’ fears about the treatment were coded as “patient concerns about side effects” or “patient concerns about treatment” and then coded by the type of concern: “hair loss,” “physical appearance,” “impotence,” etc. When these types of fears were referenced in relationship to concerns about gender, I added additional codes for “masculinity” and “femininity.” This same process on induction and deduction was used with the transcripts of patient interviews. Initial codes from the interview guide were added (*i.e.*, most

¹⁴ Social Security has a website with the most common names by decade:
<https://www.ssa.gov/OACT/babynames/decades/>

¹⁵ Refer to the interview guides in the Appendix.

difficult part of experience or learned about one's self) and deductive codes were added based on their responses.

Each cancer has a different treatment plan and prognosis, and before we can understand each cancer's gendered effects, we must first know how each cancer is treated, the side effects, and the risk of death. It should be noted that, despite the gendered location of these cancers, patients of these four kinds of cancer still share experiences with non-gendered cancer patients. Some of the side effects are not unique to the gendered cancers I study. For example, Dr. McCarthy, a medical oncologist, noted the most common side effects of chemotherapy, which is given to a wide range of cancer patients: "When you're getting the chemo, you know, knocks your hair off, nausea and vomiting, you get neuropathy, numbness and tingling, you feel tired, you can get a skin rash, blood counts drop, you might have infection or bleeding, feel—you might have some diarrhea or constipation." Thus, all patients who receive chemotherapy, which includes breast, gynecological, and some testicular cancer patients, share these unpleasant side effects with many other kinds of cancer patients. "Surgery and radiation therapy remove, kill, or damage cancer cells in a certain area, but chemo can work throughout the whole body. This means chemo can kill cancer cells that have spread (metastasized) to parts of the body far away from the original (primary) tumor" (ACS 2016). Chemo may be used to shrink a tumor before surgery or radiation therapy, it may be used after surgery or radiation therapy to help kill any remaining cancer cells, or it may be used with other treatments if cancer recurs. While chemotherapy kills cancer cells in the body more generally, radiation is more localized. The American Cancer Society (2017) explains how radiation works:

Radiation therapy uses high-energy particles or waves, such as x-rays, gamma rays, electron beams, or protons, to destroy or damage cancer cells. Your cells normally grow and divide to form new cells. But cancer cells grow and divide faster than most normal cells. *Radiation works by making small breaks in the*

DNA inside cells. These breaks keep cancer cells from growing and dividing and cause them to die. Nearby normal cells can also be affected by radiation, but most recover and go back to working the way they should. In most cases, it's aimed at and affects only the part of the body being treated. Radiation treatment is planned to damage cancer cells, with as little harm as possible to nearby healthy cells.

As a consequence of the directed treatment, side effects are generally also localized. If someone has radiation on their chest then they will only experience side effects on and around the chest. This could mean potential damage to the organs surrounding the radiation. So if someone was having radiation on their chest, it could damage their lung cells, etc. The primary side effects of radiation are redness, irritation of the skin, and fatigue.

FOUR CASES OF GENDERED CANCER

Given the location of breast, gynecological, prostate, and testicular cancer treatments, these patients also face bodily changes that are typically related to gender: fertility, sexual function, and body image. Below, I introduce each of the four cancers I study, describe their treatments, and explain the specific side effects that patients experience on top of the common side effects discussed above.

Breast Cancer

Excluding cancers of the skin, breast cancer is the most frequently diagnosed cancer in women. Thirty percent of women who are diagnosed with cancer will be diagnosed with breast cancer (ACS 2018). There will be an estimated 266,000 new cases of breast cancer in the U.S. in 2018 alone (ACS 2018). It is generally treated with surgery (a lumpectomy or a mastectomy), radiation therapy, chemotherapy, and/or hormone therapy. Depending on the stage of the cancer, women may only face one or two treatments. Chemotherapy and radiation are generally used when someone has a lumpectomy and the cancer could still be in other areas of the breast or if the cancer is later stage. Hormone therapy is only prescribed for women who have hormone-

sensitive tumors.¹⁶ These treatments block the body's ability to produce the hormones triggering the growth of their tumors. Women with HR positive tumors are placed on hormone therapy for 5 years. "The 5- and 10-year relative survival rates for invasive breast cancer are 90% and 83%, respectively. Most cases (62%) are diagnosed at a localized stage (no spread to lymph nodes, nearby structures, or other locations outside the breast), for which the 5-year survival is 99%" (ACS 2018:11).

The treatments of breast cancer have side effects that impact gendered body parts, sexual function, and fertility for breast cancer. Mastectomies and lumpectomies obviously change the shape and the appearance of the breasts, leave scars, and could result in other side effects like lymphedema and infection. Radiation can leave scarring and irritation of the breasts. In addition to the general side effects of chemotherapy, the drugs used in chemotherapy often damage the ovaries and put pre-menopausal women into menopause. Dr. Cox noted, "If they were pre-menopausal, the chemo puts them into menopause." Menopause comes with a whole host of side effects, many of which are sexual in nature, but menopause also signifies a loss of fertility. Dr. Soper explained that the chemotherapy he delivers as a medical oncologist affects his patients' fertility:

For patients who are pre-menopausal, even if they're in their 50s and they've stopped their menstrual cycle, I tell them they will go into permanent menopause and of course, they won't be able to have any more children. For younger patients, they may go into temporary menopause, but it would definitely reduce their chances of having children in the future.

¹⁶ "To determine whether breast cancer cells contain hormone receptors, doctors test samples of tumor tissue that have been removed by surgery. If the tumor cells contain estrogen receptors, the cancer is called estrogen receptor positive (ER positive), estrogen sensitive, or estrogen responsive. Similarly, if the tumor cells contain progesterone receptors, the cancer is called progesterone receptor positive (PR or PgR positive). Approximately 80% of breast cancers are ER positive. Most ER-positive breast cancers are also PR positive. Breast tumors that contain estrogen and/or progesterone receptors are sometimes called hormone receptor positive (HR positive). Breast cancers that lack estrogen receptors are called estrogen receptor negative (ER negative). These tumors are estrogen insensitive, meaning that they do not use estrogen to grow. Breast tumors that lack progesterone receptors are called progesterone receptor negative (PR or PgR negative). Breast tumors that lack both estrogen and progesterone receptors are sometimes called hormone receptor negative (HR negative)" (NCI 2017).

Menopause also results in changes to libido, hot flashes, night sweats, mood swings, depression, and vaginal dryness (Fayed 2018).

Gynecological Cancers

Gynecological cancers are less prevalent than breast cancer. Of the women I interviewed with gynecological cancer, the majority had ovarian cancer. The American Cancer Society estimates that in 2018, about 22,240 new cases of ovarian cancer will be diagnosed and 14,070 women will die of ovarian cancer in the United States (ACS 2018). “Ovarian cancer accounts for just 2.5% of all female cancer cases, but 5% of cancer deaths because of the disease’s low survival. This is largely because 4 out of 5 ovarian cancer patients are diagnosed with advanced disease that has spread throughout the abdominal cavity” (ACS 2018:28).

“Ovarian cancer survival rates are much lower than other cancers that affect women. Most ovarian cancer patients (60%) are diagnosed with distant-stage disease, for which 5-year survival is 29%. As a result, the overall 5-year relative survival rate for ovarian cancer is low (47%)” (ACS 2018:36). If the cancer is found before it has spread outside of the ovary, the five-year relative survival rate is 92%. However, only 15% of all ovarian cancers are found at this early stage because its symptoms are often not detected (ACS 2018). Ovarian cancer rates are highest in women aged 55-64 years. The median age at which women are diagnosed is 63. (ACS 2018).

Treatment for gynecological cancers includes the surgical removal of the ovaries, fallopian tubes, uterus, and omentum (fatty tissue attached to the internal organs) and/or chemotherapy. Most of my respondents had ovarian cancer and were treated with chemotherapy and surgery. The surgery often leaves women with large scars down the entirety of their

abdomen, from chest bone to pelvic bone.¹⁷ Ovarian cancer is also known to have a natural tendency for recurrence (ACS 2018). Approximately 70% of women diagnosed with ovarian cancer will experience a recurrence (OCRFA 2016). Many of the women I interviewed had recurrent ovarian cancer. Recurrent ovarian cancer is treated with chemotherapy.

Women with other gynecological cancers like cervical, rectal, or uterine may be treated with surgery, chemotherapy, and/or radiation. These treatments result in severe side effects that impact gendered parts of their bodies, their sexual function, and fertility. Surgery results in the removal of the ovaries, which drastically lowers estrogen levels that result in immediate menopause if the person is not already post-menopausal. Chemotherapy can also shut down the ovaries and put women into menopause. Dr. Soper, a male medical oncologist explained, “Women whose hormones are all changed because they’ve had their ovaries removed and then they’ve got surgery and scarring and we use radiation and then it gets more scarred.” Dr. McLean, a gynecological oncologist, said, “When someone is pre-menopausal and you remove their ovaries they go through these horrible symptoms of menopause which resolve, but there still can be an annoyance for patients.” While most patients who are diagnosed with ovarian cancer are post-menopausal, women can be diagnosed with gynecological cancers at younger ages. Dr. McLean echoed, “They get hot flashes and intercourse is painful because the vagina is dry. Their libido might change.” The removal of the ovaries in a hysterectomy result in the above-mentioned side effects.

Radiation to the pubic area also has drastic side effects. Dr. Munoz explained how radiation can close or alter the shape of the vaginal opening, “Or in patients that receive radiation because we really do change the, you know, the contour of the vagina and how well it’s

¹⁷ Robotic surgery is becoming more common and leaves women with significantly less scarring. Many of the women in my study did not have the opportunity to elect robotic surgery though some of them did.

lubricated and so on and so forth which makes intercourse sometimes more uncomfortable.”

Additionally, radiation can lead to tearing of the skin surrounding the area, including around the rectum and the vagina.

Prostate Cancer

Like breast cancer, prostate cancer is also fairly common. One in seven men may be diagnosed with prostate cancer in their lifetime, “An estimated 164,690 new cases of prostate cancer will be diagnosed in the US during 2018” (ACS 2018). Prostate cancer affects older men—97% of diagnoses occur in men 50 and older. Prostate cancer is also generally less aggressive and grows slowly over time.

“The majority (91%) of prostate cancers are discovered at a local or regional stage, for which the 5-year relative survival rate approaches 100%. The 5-year survival for disease diagnosed at a distant stage is 30%. The 10-year survival rate for all stages combined is 98%” (ACS 2018). The old adage from my respondents is that “You’re more likely to die *with* it than *from* it.”

Given that prostate cancer is less aggressive, some men opt to carefully observe their cancer’s progress (called active surveillance) instead of undergoing immediate treatment. When deciding on a course of treatment, men who have been diagnosed with prostate cancer have the option between surgery or radiation. Hormonal therapy (nicknamed “chemical castration” because it shuts down the production of testosterone) or chemotherapy may be used in advanced cases where the cancer has spread outside of the prostate. Patients diagnosed with localized prostate cancer generally see a radiation oncologist and a urological surgeon to decide between radiation or surgery. The side effects are generally the same for radiation or surgery and most patients discuss choosing the treatment solely on which doctor they felt more comfortable with

or preferred.

If men decide to treat their prostate cancer, they face side effects that impact their gendered body parts and sexual function. For men being treated for prostate cancer with either surgery or radiation, treatment often leads to urine leakage and erection problems (incontinence and impotence). Dr. Katz, surgeon, noted, “The two main problems are urine leakage and erection problems.” Dr. Pohren, surgeon, echoed, “Changes in urinary and sexual function are the most feared side effects. Then you can also have local complications and problems.” Dr. Cox, a radiation oncologist, said:

The [radiation] is instead of surgery, yeah. They’re felt to be equivalent options for curing patients with early stage prostate cancer. So patients get to make a choice nowadays, so that’s getting back to the, you know, the high socio-economic status and well educated patients tend to have much more of a need to feel like they’re controlling their destiny and making their own decisions and that kind of thing, and so for those patients it’s great. You explain the options, they get to feel like they’re choosing the one that’s best for them, there are two options that have the same survival 15, 20 years later, so they get to choose based on what they perceive as the best treatment for them.

Whereas the ones that don’t read as much and are not as proactive about learning about this, they’re going to have a tougher time. They want a doctor who just tells them this is the best treatment, this is what you need. And I’ll say this on tape but I probably shouldn’t. The surgeons are much more likely to say yeah, surgery is the best even though there’s no evidence for that at all.

When I meet with the patient, I don’t feel comfortable making that decision for them. I want to tell them, you know, you can have surgery, it’s perfectly fine. Your chance of being alive 20 years from now are exactly the same. So you need to make a choice based on what side effects you’re willing to put up with.

There is some believe that radiation will create fewer side effects because the nerves are not being cut but surgeons now specialize in nerve-sparing surgery and robotic surgery that help eliminate risks of side effects. Many patients still opt for the surgery because they want to have the cancer “taken out.”

Hormone therapy is only used when someone’s prostate cancer has recurred or spread

(metastasized). Hormone therapy essentially stops the body from producing testosterone. The drugs used are the same drugs that were historically used to chemically castrate men and both patients and doctors connect hormone therapy to chemical castration. Dr. Sledd, a medical oncologist, “Sometimes for prostate cancer we have to put them on hormones, which is basically like your chemical castration for them.” If the cancer has not spread outside of the prostate or metastasized in other parts of the body, hormone therapy and chemotherapy are not advised.

Testicular Cancer

Like gynecological cancers, testicular cancer is also less common (7.2 per 100,000). It is, however, the most commonly diagnosed cancer among men between the ages of 15 and 44 (ACS 2017a). The American Cancer Society estimates about 8,850 new cases of testicular cancer in the United States for 2017 (ACS 2017a). Testicular cancer usually can be treated successfully, overall 5-year relative survival is 95% and even cancers diagnosed at a late stage have a 5-year survival rate of 73% (ACS 2017a).

While prostate cancer is largely a disease of older men, testicular cancer is largely a disease of young and middle-aged men. The average age at the time of diagnosis of testicular cancer is about 33. Testicular cancer is treated with the surgical removal of the testicle, and more advanced cancers may require chemotherapy. Occasionally, radiation therapy is used to kill remaining cancer cells that may have escaped the tumor to nearby lymph nodes.¹⁸

The treatments for testicular cancer have several side effects that target gendered body parts and fertility. The most common surgical procedure is an orchiectomy, the removal of the testicle with the tumor. In some cases where the surgeons believe that the cancer may have spread to the lymph nodes, patients undergo retroperitoneal lymph node dissection (RPLND) where the neighboring lymph nodes are also removed. Both surgeries result in the loss of a

¹⁸ I did not have any respondents with testicular cancer that were treated with radiation.

testicle and, as a consequence, patients risk losing their fertility if the testicle removed was their only sperm-producing testicle. RPLND may cause retrograde ejaculation. “Occasionally, the delicate nerves responsible for the control of ejaculation may be damaged during the RPLND surgery. This may result in retrograde ejaculation, where the sperm is ejaculated back into the bladder rather than forward and out the penis” (TCAF 2018). The inability to ejaculate will also leave men sterile.

Chemotherapy is also used when the cancer has spread outside of the testicle. Just as chemotherapy can damage women’s eggs, chemotherapy may also damage men’s sperm and may leave them temporarily or permanently sterile. Testicular cancer patients who undergo chemotherapy also face neuropathy, nausea, hair loss, and fatigue.

DATA LIMITATIONS

Because I am only utilizing interviews, I do not have access to doctor-patient interaction. Being able to observe the interactions between doctors and patients would provide insight into the ways that doctors prescribe certain technologies and patients discuss their concerns. However, observations alone would not be sufficient because it would not provide data on how men and women define masculinity and femininity or how they discuss the changes to their gender identity. Additionally, observations alone would be limited because you could only analyze interactions during the diagnosis and treatment process. Therefore, I would be unable to analyze how identities and perceptions of bodies change after they have concluded treatment.

Another limitation to my data is that not all of the patients were treated by the doctors I interviewed. Some of these patients were treated by oncologists in my sample, but I do not disclose this information to protect both doctors and patients. However, a majority of my respondents were treated through different healthcare systems. Therefore, I cannot make direct

connections between a doctor saying that they provide a resource and a patient saying that that specific doctor did not indeed provide that resource. Instead, this dissertation analyzes cultural beliefs about gender and general trends in prescription/advice.

Lastly, there may be selection bias. There is a chance that the men and women who received my recruitment information and opted out of the interview could be different in some way from the individuals that I interviewed. For example, men with extreme concerns about their sexual function may have decided that they were not comfortable talking to a young woman about their erectile dysfunction. I cannot control for the individuals who did not participate. I can, however, try to assuage concerns that men were not likely to talk to me about sex. In this regard, my data speaks for itself. Any concern that men and women were not open with me will likely be alleviated as you read my findings. At the end of our interviews, men and women routinely noted their surprise about their own openness. The length of these interviews, especially the amount of time I devoted to listening to patient narratives and building rapport, gave people a sense of comfort, allowing them to share stories that they may not have planned to share. I too was surprised by men's and women's willingness to open up, describe their devastating side effects in detail, and discuss their fears and vulnerabilities.

CHAPTER 3: CULTURAL DEFINITIONS OF MASCULINITY AND FEMININITY

A common cultural belief is that our body parts and sexual organs inevitably and invariably dictate our gender identities and manifestations of masculinity and femininity. Scholars have long understood gender as a performance that is enacted with our bodies, as a way of portraying and expressing one's feminine or masculine self (Butler 1988; West and Zimmerman 1987). Yet there are also gendered expectations of the body in its appearance and function. Culturally, we assume that what we do with our bodies and what our bodies look like reflect our masculinity and femininity. As a consequence, we think that gender is inherent in our bodies, biologically and naturally (Butler 1988; Butler 1990; Crawley et al. 2008). Our gendered "self" is created through these gender performances (Martin 1998; Mead 1934; Young 1990). Therefore, the disruption to the gendered body as a consequence of cancer treatment provides a unique opportunity to study how individuals reproduce or challenge cultural schemas of gender with their own gender identity. In this chapter, I analyze how cancer patients and those who treat them draw on definitions of masculinity and femininity. In order to problematize and analyze the social consequences of having a gendered cancer, we must first understand how these individuals define masculinity and femininity.

Below, I show how patients and oncologists draw on cultural definitions of masculinity and femininity in narrow ways. I find that oncologists and patients conflate masculinity with sex and potency, defining masculinity by men's ability to appropriately engage in sexual activity. Alternatively, I show the ways that they define femininity in relation to presentation and appearance, focusing exclusively on how cancer challenges women's ability to look and feel feminine. Cancer alters *both* men and women's bodies in ways that affect their appearance and sexuality; however, masculinity and femininity are defined in particularly narrow ways. Men

with prostate cancer and testicular cancer face changes to their physical body that affect their appearance, and women with breast and gynecological cancer deal with side effects that can challenge their sexual function; however, these issues are rarely discussed in relation to understandings of masculinity and femininity among my interview respondents. Additionally, broader definitions surrounding expected gender roles and gender performance—such as being able to take care of children, go to work, clean, and cook—are entirely ignored in my respondents' discussions of what it means to be masculine and feminine.

How patients and oncologists define masculinity and femininity is particularly important to understanding the cultural expectations surrounding changes to the gendered body. Additionally, as doctors have power and authority to change cultural understandings and social discourse (Martin 1991), it is significant to understand how they define masculinity and femininity within a medical context.

In this chapter, I first outline how male and female oncologists conflate masculinity with potency. Next, I explain how testicular and prostate cancer survivors define the cultural notion of masculinity through sexual function, regardless of whether they feel that sexual function is their primary concern or a major part of their own masculine identity. While men are clear that they have experienced these symptoms, many argue that it is not at the heart of their understandings of their *own* gender identity. Then, I show how oncologists define femininity with issues surrounding women's appearance. Oncologists' focus on feminine appearance is almost exclusively breast-centric and seen as significantly important for their patients' assumed male partners. Lastly, I describe the ways that breast and gynecological cancer survivors connect femininity with appearance. Similar to the oncologists, female survivors define femininity through narrow understandings of what it means to *look* like a woman, however, patients draw

on broader definitions of what it means to look feminine outside of the breast-centric views of the doctors. Similar to their male counterparts, women rely on broadly shared notions of femininity, but many of them argue that even as their bodies have changed, their experience with cancer has not weakened their own gender identity.

MASCULINITY AND SEXUAL FUNCTION

Given that we are in an era of evidence-based medicine where doctors are paid through a fee-for-service model and have less and less time to spend with patients, we might expect that oncologists (especially surgeons and radiation oncologists) would not have time to discuss psychosocial concerns with their patients.¹⁹ However, the oncologists I interviewed assert that they have lengthy discussions with patients. Most state that these conversations are necessary to build trust by allowing patients to talk openly about their concerns, including questions about how their disease and treatment are affecting their masculinity and femininity.

Oncologists: “They’ll equate not having sex with masculinity”

Oncologists jump straight to discussions of potency when discussing masculinity and state that erectile dysfunction is the primary concern of their male patients undergoing treatment for prostate cancer. I did not ask respondents specifically about sex. The question generally was along the lines of, “Do patients express concerns about their masculinity?” Occasionally the question was worded, “Do your patients express concerns over masculinity or a loss of self as a man?” Oncologists were allowed the opportunity to define masculinity however they wanted, yet they jumped straight to discussions of sexual function. This direct connection between

¹⁹ I asked each oncologist questions related to their patients’ apprehensions about cancer treatment and the side effects (this was usually when oncologists mentioned their patients’ fears related to gender). It is important to note that I did not ask specifically about sexual function or appearance but rather asked open-ended questions about masculinity and femininity and let the respondents draw their own conclusions about what that meant. This interview approach allowed me to more clearly understand the cultural schemas that oncologists draw upon when discussing changes to the gendered body.

masculinity and potency without probing shows the importance of sexual prowess and erection within the cultural discourse surrounding masculinity and male bodies.

When I asked Dr. Sheila Richardson, a radiation oncologist, about masculinity, she stated, “A lot of men are very unhappy to have their prostate cancers treated because one of the potential side effects is erectile dysfunction and they get very unhappy when they hear that.” Since Dr. Richardson jumped to erectile dysfunction when I asked about masculinity, we can see the strength of her association between masculinity with the act of sex. Additionally, Dr. Alex Munoz, a radiation oncologist, said,

Well yeah, they’ll equate not having sex with masculinity. So they’ll think that it hurts their masculinity if potency is decreased. They don’t think of masculinity in a broader sense. They’ll just think if it’s sexual function and they can’t do it [have sex] then they’re not men.

Dr. Munoz puts potency at the heart of masculinity. He notes that having sex and a virile sex life is a defining characteristic of what it means to be a man. Similarly, Dr. Christopher McCarthy, a urological medical oncologist, said, “It has a lot of side effects that sort of go right to the root of what it means to be a man, you know. And so this is a big issue.” Dr. David Katz, a urological surgeon, described the connection between impotence and his patients’ concerns about not feeling like a man anymore:

I guess that’s a clinical way of thinking about a sexual function, orgasmic function, erectile function, you know, seminal admission, I mean, the different domains of sexual function. But for a man, it could just feel like not being whole. And they’ll describe it that way. “I’m not the same. I’m not a man anymore.” So, there’s more basal meaning almost to the loss of functioning for men that they will express sometimes.

When I asked them about masculinity, Drs. McCarthy, Katz, and Munoz dove into discussions of erectile function and men’s ability to engage in sexual intimacy. Relying on cultural understandings of masculinity, they see sex as a necessary requirement for feeling like a man.

Not only do doctors report that their male patients are concerned that they are not or will not be ideal men because of their decreased libido or impotence, but many doctors say that their patients are concerned that they will be more like women as a consequence. Therefore, oncologists define masculinity in opposition to femininity. Dr. Tom Pohren, a urological surgeon, said, “They usually relay their fears jokingly and some even address them unguardedly, they often are concerned that they’ll be like women and I try to dispel those illusions that they’re going to be women now.” That fact that these feelings are expressed as *fears* is important in understanding how men might feel to be seen as less masculine. Dr. Jerry Ellison, a radiation oncologist, explained that in some instances, prostate cancer patients have hormone therapy that turns their testosterone production off. He told me:

They also start having hot flashes so they feel like their wives. They go through what their wives went through. The wives love it, but the men feel like, you know, “I’m in menopause? I’m a man, I’m in menopause?” And they lose lean muscle mass and they can gain fat round the middle so it does a lot of things. So it does a lot of things that they feel less like men.

Because masculinity and femininity are defined in opposition to one another, experiencing menopausal symptoms similar to that of women makes men feel even less like men. Culturally, hot flashes are indicative of the female experience, so when men experience a similar symptom to their wives, they express fears of being less masculine.

While oncologists report men’s concerns surrounding masculinity and impotence, many oncologists do not believe that impotence is actually the worst side effect of cancer treatment. Oncologists believe that incontinence could affect a patient’s quality of life more than impotency. When I asked Dr. Pohren what side effects his patients are most concerned about, he responded definitively, “Erections. And I don’t really know what that’s a function of, maybe it’s a cultural thing, but it’s easier to treat erection problems, if I were them I would worry more

about urinary leakage because that impacts your daily life in significant ways.” Dr. Rebecca Payne, a medical oncologist, agreed,

If you are incontinent, that really ruins your quality of life. You know if you have to wear a pad, I mean you can’t function in the same way as you did before. So that could ruin your job for example. [They] tend to be more concerned, maybe a little bit more about impotence, although I think they should be more concerned about the other [incontinence].

Impotence is assumed to be the defining characteristic of masculinity even though oncologists believe that incontinence could pose a greater threat to a patient’s quality of life. While wearing a pad and the loss of a testicle (a defining male body part) could both potentially challenge a man’s perception of masculinity, doctors do not make the connection between these side effects and masculinity. It is significant that oncologists connect masculinity with sexual function alone, reinforcing the salience of sexuality with masculinity. This demonstrates the prominence of hegemonic masculinity. Oncologists draw on cultural definitions of hegemonic masculinity that assume that sexual function is at the heart of being a man (Connell 1987; Douglas 1970; Lorber 1994; Ridgeway 2011; West and Zimmerman 1987).

Since oncologists view the performance of a sexually active masculinity as patients’ largest concern, oncologists respond by prescribing technologies and medicines to treat and “fix” erection problems. This will be discussed more in Chapter 6 and the Conclusion.

Male Survivors: “Masculinity, see that’s what this whole thing is all about”

Similar to their oncologists, survivors of testicular and prostate cancer define masculinity almost exclusively around potency and sexual function. While survivors connect masculinity with sex, I came across an unexpected twist: most survivors are clear that the changes to their sexual function have not actually weakened their own gender identity. In this section, I will outline how men define masculinity in a narrow way, similar to their doctors’ definitions. Then, I

will explain how these men discuss how the changes to their sexual function have affected their own gender identity, if at all. Surprisingly, most men argued that their own masculine identity is not connected to their sex life. Only three male respondents made a direct connection between their own masculine identity and the changes to their sexual function, and only two male respondents acknowledged experiencing difficulty managing the loss of potency.²⁰

When I asked Thomas, a 75-year-old prostate cancer survivor, about masculinity, he said, “And so if you say masculine, to me, to feel like a man is to have sex regularly with a woman, you know.” Masculinity for Thomas is explicitly about heterosexual sex. Thomas reinforces the broader cultural concept of masculinity. Similarly, John, an 81-year-old prostate cancer survivor, connected sex, libido, and masculinity:

It changes your masculinity, cancer does. It affects your libido. You don't think about sex, you don't think about that. And you are aware of other men that this is a very major part of their life and it isn't in mine. And I substitute other things for that. *Masculinity, see that's what this whole thing is all about. That's the problem.* (emphasis added)

John sees the loss of libido and sex drive as the heart of masculinity and thus the heart of the problem with men and prostate cancer. When I asked about masculinity, Eric, a 42-year-old testicular cancer patient, started with, “A manhood standpoint, a sexuality standpoint, a physical relationship standpoint...” connecting masculinity with sexuality and physical, intimate relationships.

Three of the men I interviewed, Larry, Frank, and Thomas, did base their masculine identity on their sexual function. Larry, a 70-year-old prostate cancer patient who was being treated with testosterone inhibitors to slow his aggressive cancer, defines masculinity in similar

²⁰ While one could guess that men did not feel comfortable talking to a younger woman about their sexual function, I would like to point out that most of them were incredibly open about the changes to their bodies and the loss of potency that they experienced. Some men throughout the interview or at the end of the interview even expressed surprise that they were as open about their sex lives as they were. Thus, the men I interviewed did not feel uncomfortable talking about sex, they were just adamant that the changes to their sexual function were not the most important part of their own masculine identity.

ways to John and Eric. However, Larry reported feeling castrated. When I asked him about changes to his masculinity, Larry spoke at great length about the loss that he felt.²¹

I think I've been robbed of my masculinity. I was selective about the women I was with. There was a lot of joy that brought me. I feel like that because of the castration that that joy is removed not only from my lady friend and me but also just the joy of the sexual tension between people. If I saw a woman that I found attractive there was certain pleasure I would get from an encounter or whatever with her whether not necessarily had to lead to sex but it was a sexual sensual encounter. That's all robbed, and that was something that was big in my life because I had learned this specific technique.

Without prompting, Larry immediately began discussing sex, intimacy, and physical relationships when thinking about masculinity. Larry feels like he has been robbed of this sensitive intimate touch and sensuality. Larry's sense of castration stems from the testosterone inhibitors that he was prescribed due to his aggressive cancer. Testosterone inhibitors eliminate testosterone production, and these drugs are often coined "chemical castration." Without testosterone, men lose libido and muscle growth and experience "feminizing" symptoms like hot flashes and breast growth. Larry's quote helps us see how definitions of masculinity can also shape his masculine identity. His sexuality was an important part of his identity, and his feelings of castration mirrored his understanding of masculinity as a concept. While some men had undergone radiation, surgery, or hormone therapy that resulted in changes to their body, other men decided against treatment in fear of the potential side effects.

Frank, a 65-year-old prostate cancer survivor, decided against treatment at the time of the interview because the side effects might potentially be too damaging to his masculine identity.

²¹ In Chapter 4, I argue that relationships play a key role to understanding why some men felt that their own masculinity was damaged. Larry was one of the few single men I interviewed.

Impotence is “too high a price to pay,” so Frank decided to use “active surveillance”²² to monitor his cancer.

The prostate is just like ground zero for all of our functions. Everything kind of goes through there, and once you go in and operate the chances of nerve damage, the chances of urinary tract damage, the chances of all kinds of other periphery damage are high. You come out of the operating room, and you’ve got a big smile on your face hey, I haven’t got cancer anymore. Oh yeah I got these side effects... Now all of a sudden, your quality of life has been majorly modified, and more often than not no one has really sat down with you up front and explained this in gruesome detail of what these things might happen and are you willing to live with that if this does happen. For some men, all of those things are a non-issue either because of their age that sex is not important to them anymore. For me, I’m not 80 years old, I still hopefully have a number of years ahead of me and the issue of impotence or incontinence ride pretty high on my list. So looking at those and looking at the high incidence of those risk factors I said this is way too high a price to pay, way too high.

Sex is important to Frank’s personal masculine identity, and he connects his personal masculine identity with sexual ability while reinforcing the cultural definition of masculinity.

Ron, a 71-year-old married prostate cancer survivor, stated: “It’s—you know that is a problem, you know because you can’t—it’s hard to have sex... I knew things would change, it did effect you know man—how I felt as a man.” Here, we see that Ron’s sexual function is connected to his masculine identity. However, Ron was clear that sex was not his or his wife’s top priority.

Even men who argue that sexuality has not affected their own masculine identity define the cultural concept of masculinity with sexual function and sexual desire. Eric, a 42-year-old testicular cancer survivor, conflates masculinity with sexuality but dismisses sexuality as his primary concern because he was never particularly stereotypically masculine. However, Eric

²² Active surveillance is a treatment option chosen by some prostate cancer patients if their cancer is less aggressive. Under active surveillance, patients monitor their PSA scores over time to see if they can survive without needing radiation, surgery, or hormone-inhibitors.

states that he was more worried when he potentially had to face his mortality.²³ When I asked Eric how this experience changed his view of his masculinity, he responded:

Hard to know, I never really have been somebody who's sort of bravado, or I've taken a lot of social characteristics I think from my Mom over my lifetime, so *I've never been on the side of sexualness and extremely masculine or testosterone driven*. I'm even less likely to be bravado or to be less the caveman kind of male bravado type image. I think had I been more that way it'd be more obvious the change that happened, and I don't think that's hormonal or testosterone or the fact that I've had somewhat disfiguring surgery or that kind of thing. *I think it's more the personal experience of having to face death potentially even if only for a couple of weeks not know if it was going to be life threatening*. I think that's probably cowed by that sense in me, [it] made me a little bit more laid back, [which] in some people's minds may be less masculine. (emphasis added)

Like the other men I spoke with, Eric connects the cultural notion of masculinity with what he calls “sexualness.” When discussing their cancer, these prostate cancer and testicular cancer survivors quickly connect masculinity with sexual function, even though many of them state that it is not their primary concern. Like the oncologists, patients' definitions of masculinity are tied to potency and virility, something that is directly impacted by the treatment of prostate and testicular cancer.

Despite their definitions of masculinity, most of the men I spoke with argued that the loss of sexual function is not their primary concern and that their own masculine identity is still intact. For example, Roger, a 72-year-old prostate cancer survivor, quickly responded, “Masculinity, Jesus. I don't feel any less masculine, that's for sure. I still enjoy a pole dance, *Playboy* and all that. I mean masculinity, I'm right there. My head still turns with something attractive and I guess when it doesn't turn is when I got a problem.” While Roger states that he does not have any issues with his masculinity, he conflates masculinity with sexuality by saying that he still enjoys a pole dance and *Playboy*. Similarly, Raymond, a 72-year-old prostate cancer

²³ The relationship between mortality and masculinity will be examined in further detail in Chapter 5.

survivor, said that his perceptions of his masculinity have not changed. For him, the possible loss of sex was not an issue.

Absolutely nothing. It hasn't changed it a bit. You mean because possible loss of sex? No, not a bit. I'm not—I don't know, I don't like it [not being able to have sex]. I want to do what I can, but you just have to accept the stuff that comes with, you know.

Roger faced similar side effects to the other men and did lose his ability maintain an erection. Roger and Raymond are not happy that they cannot perform the same way sexually but realize that losing potency is just something they have to accept and argue that it does not define their masculinity. Likewise, Donald, a 75-year-old prostate cancer patient, argued,

So the surgery aspects, the sexuality part of it, didn't affect me much because that wasn't high on the totem pole for either my wife nor me. The incontinence, yes, bothers me simply because it's very, very inconvenient to have to change pads—although mine's very, very light, a pad a day is all it takes. I was not impacted so much by that.

Similar to Raymond, the loss of sexual function has not affected Donald's own masculine gender identity. He noted that this was not important for him or his wife—the role of committed relationships will be highlighted more in Chapter 4.

Another patient, 42-year-old Eric who was a family physician and had testicular cancer, expected that he would be insecure about his sexuality and masculinity, but he reported being pleasantly surprised:

You know I kind [of] thought I actually would, but no, I really haven't had much to speak of in terms of that kind of insecurity. Most of my insecurity is the concrete thoughts of, "could this come back again?" And but from a manhood standpoint, a sexuality standpoint, a physical relationship standpoint it really hasn't changed much at all. I think not nearly as much as what I've seen people go through with mastectomies or other more disfiguring surgeries when I have patients go through those.

Eric thought changes in sexual function and desire would have larger effects on his masculine identity than it did and assumed that other people would have greater issues. Because he has seen his patients fight a variety of diseases, he does not feel like his masculine identity was impacted nearly as much as others'. Men frequently highlighted the expectation that impotence would weaken masculine identity for other men but has not affected their own. As shown earlier, John, the 81-year-old prostate cancer patient who was on hormone therapy, argued that this loss would be a very major part of other men's lives; it just was not a large part of his. "It changes your masculinity, cancer does. It affects your libido. You don't think about sex, you don't think about that. And you are aware of other men that this is a very major part of their life and it isn't in mine. And I substitute other things for that." While he is very clear that having hormone therapy does in fact affect his libido, John also insisted that this was not a large part of his life and that his masculine identity was not connected to his sex life.

When asked how testicular cancer had affected his masculinity, 29-year-old Daniel stated:

I don't know if it changed my perception of myself as a man. The whole like, you know, when I was first diagnosed my doctor talked about like, you know, removing a testicle and stuff like that. I was knowing that I was—this idea of manhood and masculinity and having two balls at all, right. *My* idea of masculinity or being a man wasn't tied up in *my* physical appearance. You know my dad I think showed me that being a man has to do with responsibility for those you care about and I think that that's still there. So really I don't think of it too much in a way like that. I mean like the stubborn part of me that's like, you know, I'm probably more of a man now than I was before all this happened because of it. Like [I've] been through some shit that a lot of guys haven't, so if you think that you're more of a man than me because you have two balls, you have no clue what you're talking about. So I think my identity as a man, you know, it's not for me to worry about because I'm a survivor and that's it.

When Daniel says "I don't think of it too much in a way like that," Daniel dismisses cultural definitions of masculinity surrounding sex and physical appearance because *his* masculinity is

not tied up in those things. Daniel assumes that other men would struggle with issues about masculinity, but he explained that he simply does not have this issue. Daniel acknowledges that, “That’s probably a minority opinion, but my manhood isn’t really associated with my sex drive so much.” For Daniel, his masculine identity is not associated with his sex drive, and he attributes his minority opinion to his education and the way he was raised by his dad. He recognizes that he might be an outlier because of his Ph.D. in philosophy, but he is particularly interested in the ways that other men connect masculinity and identity:

Yeah, I would be interested especially in terms of like masculinity in the area of identity of a man, how the cancer affected particularly with different age groups like older versus younger. That’s very interesting. I’m probably an outlier because I have this weird sense of masculinity that’s associating, you know, from philosophy.

Daniel assumes that he has a “weird sense of masculinity” because of his background studying philosophy, but he still accepts that most men would define manhood with sex drive. Like most of the respondents, Daniel defines masculinity in very narrow terms, even if he does not accept them as his own. He sees his own understanding of his masculinity as different and distinct from cultural definitions.

While survivors and their oncologists rely on a narrow cultural definition of masculinity defined exclusively by sexual function and potency, I argue that the relationship between cancer and masculinity is more intricate and complex. Most of the men I interviewed were explicit that they did indeed face side effects that could damage their masculinity and likely damaged others’, but that their own masculine identity was intact. As I will show in Chapter 5, cancer damages men’s masculine identity in numerous ways aside from their potency. Throughout this dissertation, I will explore the various ways that gendered cancers challenge men’s identity, the

consequences of this conflict for my respondents, and some of the conscious and unconscious strategies that they have for handling these changes.

FEMININITY, APPEARANCE, AND SEX APPEAL

Shifting from the definitions of masculinity to the cultural understanding of femininity, I will start by outlining the responses from my interviews with oncologists. When answering questions about femininity, oncologists jump to discussions about physical appearance, sex appeal, and the sexual desires of (implied male) partners. Just as I asked oncologists who work with male patients broad questions surrounding masculinity or a loss of self, oncologists who work with women could define femininity however they wanted or with whatever came to their mind first. According to oncologists, physical appearance and women's desires to please men are the defining characteristics of femininity and the largest concerns for their female cancer patients. For oncologists, discussions about femininity and physical appearance were almost entirely breast-centric. Dr. Jeffrey Soper, a medical oncologist who works with breast cancer patients, stated, "So, body appearance, particularly related to breast surgery is clearly an issue. I frequently talk with patients about it." Similarly, when I asked Dr. Stacy Yarborough, a breast and gynecological radiation oncologist, about whether patients had discussions with her about femininity she answered, "Oh absolutely, absolutely. Some of them, you know, they come to me and they had their surgery four, you know, four weeks ago and they said 'I've not even looked at my breast. I can't even look at it. I haven't even—I have no idea how it's doing because I don't look. I dress in the dark.'" Drs. Soper and Yarborough both assume that femininity is connected to body appearance, specifically focused on the appearance of the breast.

According to oncologists, women are also worried about how their partners will perceive the change in appearance of their breasts. Doctors routinely mentioned women's concerns about

not looking feminine enough for their husbands, boyfriends, or future heterosexual partners. The assumption was almost always that women's concerns are about how *men* would view them; thus, doctors generally presented these concerns in heteronormative terms. This directly links cultural definitions of femininity to sex appeal and the male gaze. Dr. Matthew Cox stated, "They don't think their husbands find them attractive anymore." He continued,

Conversations about whether they're worried that their husband is going to look at them differently after breast cancer treatment, whether they have a mastectomy or not. I think younger women are more likely to open up about that. "I'm going to lose my breasts, I'm single" or "I'm 32 years old, I don't want to be disfigured, I want to keep my breasts." And so they're more likely to think about it or to talk about it in those kinds of terms.

Dr. Rebecca Payne also related breast cancer patients' issues with their body image to concerns about sexual relations with men.

I think some women are worried about their relationships with their husbands. About their sex life afterwards being altered and not having sort of the same image of their body that they had before that was important for their relationship. The younger the woman, usually the more that is important.

Oncologists noted that feminine appearance, particularly the look of the breasts, is important for women and their concerns about physical intimacy with male partners. While they note that age plays a role in how women feel about the changes to their bodies, oncologists still define femininity in relationship to the physical appearance of the breasts to satisfy the male gaze.

When issues of sexual function are discussed in relationship to femininity, they are problematized differently than in discussions about masculinity. Discussions of sexual function for men generally focus on men's own sexual satisfaction, while for women it is seen as more about pleasing their partner. For example, Dr. Matthew Cox, a radiation oncologist, stated, "I'll sit there and these old guys, they'll talk about how they are so worried and they are so upset [about their impotence] and the wife is like, 'Oh, please,' you know?" Dr. Cox noted that his

older male patients will express concern about their sexual function even though their wives will joke that they already are not having much sex anyway.

However, when sexual function is addressed for gynecological patients, their concerns are presented as centering on the pleasure of their heterosexual partners. Just as oncologists note that looking feminine is intended to please the male gaze, sexual function also centers on pleasing (male) partners. For example, Dr. Robert McLean explained:

Something that may affect their sexuality has a significant bearing in terms of how they view themselves at times or they're concerned of how their spouse or boyfriend is going to feel about them. And a lot of that's not founded on reality, but it's what they think. And that's what's important, you know. Whether it's real or not, it's how they feel.

This sentiment can be also be seen in a statement by Dr. Stephanie Lake, a radiation oncologist:

Probably because I don't know—like I mentioned the sexual function is extremely important to men. And, probably—and then, on the reverse side, when we see women going through GYN treatment, you know, usually that's not as big a concern, unless they're concerned about their partner. You know, the female is concerned that their partner will be upset. You know, that they're not able to be sexually active.

Dr. Lake highlighted this key difference. A change to women's sexual ability is only seen as a concern if it affects their partner. Therefore femininity, as defined by the appearance of women's breasts or in relationship to sexual function, is coupled with sex appeal and men's desire.

Oncologists claim that men are concerned about not having sex, while women are concerned about not being sexually attractive or available for men.

Oncologists: “Luckily, I’m not dealing with breasts and prostate.”

As a consequence of conflating masculinity with sexual function and femininity with being sexually attractive and pleasing to a partner, in our interviews, oncologists generally directed their attention to breast cancer and prostate cancer. Breast and prostate cancer are seen as the trademark cancers in regards to gender because they directly affect our cultural definitions

of masculinity and femininity. The immediate focus on prostate cancer and breast cancer almost exclusively shows the limited definitions that oncologists draw upon. This was even true for oncologists who treated women with gynecological cancers or men with testicular cancer. These oncologists swiftly stated their patients did not address concerns about masculinity or femininity because they did not work with prostate or breast cancer. For example, one male urologist said:

I think that luckily since I'm not dealing with breasts and prostate that these issues are less common. That doesn't mean that a big incision that you put on their side doesn't hurt or doesn't cause a significant degree of angst, but generally in terms of immediate body image side effects or things like that, kidney cancer doesn't quite have that.

Similarly, a gynecological oncologist noted that femininity is not an issue for his patients.

However, he imagines it would be a significant issue for breast cancer patients:

I would imagine that would happen more often with breast surgery than with gynecologic surgery. Even though we're dealing with the female organs. I get that. *It's not an organ that you can see.* So, you know, it helps identify you as a woman, but it's not the same outward appearance. It's not like you look in the mirror and you see that you've had a hysterectomy. (emphasis added)

This doctor's belief that only women with breast cancer would face issues with femininity because you cannot see a hysterectomy truly exemplifies the limited cultural definition of femininity focused exclusively on appearance that informs his response.

I also interviewed an older radiation oncologist, Dr. John Swinski. As a radiation oncologist, Dr. Swinski has worked with both gynecological and breast cancer patients. While he currently works with primarily gynecological cancer patients, in a previous position, he treated female patients with breast cancer. When I asked him how his current patients felt about issues of femininity, he stated, "This is a subject matter that doesn't actually come up in the conversation very often... We talk about the sexual aspects that might be affected by the radiation, but it doesn't seem to have a huge impact on most women." He then immediately

turned his attention to his previous experience with breast cancer patients and stated, “Femininity of mastectomies was a bigger issue for most women than what was happening with gynecologic areas.” Dr. Swinski conflates femininity issues with the issues that breast cancer patients faced about appearance and ignores how the sexual side effects of radiation on women with gynecological cancers might also affect femininity.²⁴ His understanding of the difference between gynecological cancer patients and breast cancer patients highlights my point that femininity is constructed around feminine appearance.

Both male and female oncologists define masculinity almost exclusively in terms of sexual function and femininity in relation to women’s appearance or sex appeal. While some oncologists are clear that they do not think that these concerns should be of primary importance for their patients, they still draw on limited conceptualizations of what it means to be masculine or feminine. Oncologists draw on cultural conceptions of hegemonic masculinity and emphasized femininity but ignore many other aspects of masculinity and femininity that could be affected by these cancers. This is most obvious when doctors do not think to discuss how male cancers change men’s physical appearance and women’s cancers affect their own sexual function and desire. Therefore, prostate and breast cancer receive the most attention, while the potential gendered concerns for testicular cancer and gynecological cancer patients may be ignored.

Female Survivors: “A lot of your femininity is your breasts”

Just like their oncologists, women with breast cancer and gynecological cancer draw on cultural definitions of femininity that are tied to expectations about *looking* feminine, focusing predominantly on how they look to men. Twenty-eight of the 32 women I interviewed connected femininity with appearance, placing importance on how women’s bodies, clothes, and hair look. Below, I will start by quickly showing how women define femininity. Secondly, I will give a few

²⁴ For more information on the side effects, please refer to Chapter 2.

examples of women who do report feeling a sense of damage to their own gender identity because of the changes to their appearance. Yet, thirdly, I will explain that most of the women I interviewed feel that their own gender identity remained intact after the changes to their bodies from their experience, even though these women hold the widespread appearance-centric cultural understanding of femininity.

Throughout my interviews with breast cancer and gynecological cancer survivors, women conflated femininity with looking feminine. Like the oncologists who assumed breast cancer patients had bigger issues, women who had not had radical mastectomies assumed that the women who had would have more damaged gender identities. This was seen by women with lumpectomies and gynecological cancer patients. These assumptions show how salient appearance was to cultural understandings of femininity. And time and time again, regardless of the respondent femininity was conflated with looking feminine. However, women's discussions of looking sexy or attractive went beyond the oncologists understandings of just the appearance of the breasts, to include discussions of scarred bodies (scars on abdomen, etc.), wearing attractive underwear, and looking sexy with make-up, wigs, and clothes. Women defined femininity by relying on cultural understandings of women as sex objects but defined this in broader terms than the oncologists did. The cultural definitions used by women are evident throughout their responses, even though a majority of my respondents state that their own gender identity has not been damaged.

Additionally, Tammy, a 51-year-old breast cancer survivor, said, "Yeah, it hasn't changed it at all, it hasn't. I still like matching underwear and bras and things like that. I just have a scar now. I might have been different if I had lost my breasts but I am okay with my femininity for now." Tammy connected femininity with wearing matching underwear and

changes to her body. While she did not have a complete mastectomy, and it is unclear if she would feel differently if she had, Tammy does not feel like her feminine identity has changed at all. Like Tammy, other breast cancer survivors who had lumpectomies rather than mastectomies did not report a change in their personal feminine identity. Margaret, a 60-year-old breast cancer survivor, said, “I didn’t lose my breasts. I think if I had lost my breast it would have been a lot worse.”

When I asked Diane, a 63-year-old breast cancer survivor, why she chose a lumpectomy over the mastectomy, she responded, “I guess I had hopes of having a sex life after this.” Diane expressed concern that her appearance after a mastectomy would ruin her sex life. Because she did not want to have reconstruction, she decided to undergo the chemotherapy and radiation instead of having the mastectomy. Diane assumes that the loss of a breast would prevent men from wanting to have sex with her. Here, feeling and looking attractive are conflated with femininity. Ultimately, her decision not to have the mastectomy left her own gender identity intact. “Having had the lumpectomy, that—you know we talked about that before. I just—I think that probably preserved it so I still—I still feel the same.” Like Diane and Tammy, many gynecological cancer and breast cancer survivors who did not have a full mastectomy note that they might have felt less feminine if they had had their (entire) breast removed. Their perception that losing a breast or losing more of their breast would affect their feminine identity highlights the significance of appearance in their cultural understandings of femininity.

While 28 of the 32 respondents defined femininity through appearance and sex appeal, only a minority of the women I spoke with based their own gender identity on this appearance-centric notion of femininity. 3 women explicitly noted damage to their own feminine identity and 2 felt a connection between the changes to their bodies and their sense of self and femininity.

Here, I will provide brief glimpses into Carolyn's and Rebecca's stories and the ways they examine change to their feminine identities.²⁵ When asked how cancer has changed her femininity, Carolyn, a 56-year-old breast cancer survivor, immediately connected femininity with appearance. Carolyn had had a lumpectomy, and when the margins were not clear, she underwent a double bilateral mastectomy. She said, "Yeah, so I don't feel like I'm as attractive as I was before. You know, I don't think that he [my husband] loves me any less but I just don't—I don't feel as attractive as I did before." For Carolyn, her immediate connection to femininity is tied to feeling attractive for her husband. Carolyn's own sense of gender identity has been damaged as her surgery made her feel less attractive.

Similarly, Rebecca, a 55-year-old uterine cancer survivor, noted that she dresses differently post-cancer:

I'm vain. I could not be one of those people that can walk around bald, no way. No way. I felt I looked like a dork. And then several of my friends when we're all baldies. No, it's like you're looking at someone and you only recognize them for their feature of their eyes or it's their mouth or their nose. All of a sudden it shrinks. It's like it is you, it is you. Yeah. *So I am still a woman and I've noticed I'm more conscious of dressing when I do go out. I want to look like a woman.* It's probably increased it 'cause I am compensating for not having other things, which people don't know. You know people don't know that I need to. (emphasis added)

For Rebecca, it is very important that she *looks* like a woman. She struggles to maintain her feminine identity post-cancer, even though she still has her breasts. Unlike the gynecological oncologist who said that his patients do not have femininity issues because you cannot see a hysterectomy, Rebecca feels like she needs to look feminine to compensate for the changes that people do not see. Simply by looking at her, one would not know that Rebecca has had a hysterectomy, but she still feels the need to compensate for not having these internal organs.

Thus, Carolyn and Rebecca's own feminine identities were closely tied to the appearance-centric

²⁵ Karen is another example of a woman who expressed noted feeling damaged because of the loss of her breasts. Her story will be told in detail at the beginning of Chapter 4.

cultural understanding of femininity, and their identities had been damaged by the changes to their bodies.

The cultural emphasis on feminine appearance has also shaped the actions of another breast cancer survivor, 52-year-old Kimberly. Ever since her lumpectomy, she feels that it is important to dress sexier for her husband and to look more feminine at work.

I've actually become more feminine because of this experience. I try to dress a little bit more sexier for my husband now. I bought sexy underwear. So it's interesting, because I was never a girly girl. And now I—I take more effort to—not on my days off obviously but when I go to work, I take more effort to look good and dress well. An—all my old favorite clothes that have holes in them, I got rid of them. That is an interesting consequence of what I went through, and I don't know why all of a sudden it matters to me that I look good. But it kind of does, so I don't know.

Thus, Kimberly's feminine identity is tied to being sexy for her husband and putting more effort into her appearance at work. Her cultural conception of femininity is tied to women looking sexy, and, surprisingly, she argues that her own feminine identity has not been damaged by cancer but enhanced.

Rebecca and Kimberly define femininity by appearance, but they rely on a broader definition of what it means to *look feminine* than the oncologists. While oncologists were almost entirely breast-centric in their discussions of appearance, most of the women who I interviewed used a broader definition of looking feminine by focusing on things such as clothes, underwear, and make-up.

Like Kimberly, women repeatedly connected femininity with appearance, the majority of the women I interviewed did not report that cancer had left them with a weakened feminine identity. Just like men who conflated masculinity with sexuality but stated that their own masculine identity had not been challenged, many women said that they were learning to see their femininity as more than just their breasts and appearance. Twenty-seven of the women I

interviewed said that their own gender identity has not been damaged in the ways that we could expect. While some women felt that their own gender identity was injured because their appearance had been altered, I will also show many examples of women who articulate that femininity is about appearance but has not necessarily been hard on themselves.

Felicia, a 42-year-old breast cancer survivor, said, “It definitely changed—in many ways it heightened my awareness of myself. My acceptance and belief in the fact that my femininity is more than just my hair and just my boobs; irrespective of that, I am still a woman. It wouldn’t matter you know.” Felicia draws on the cultural conception of femininity with her reference to hair and breasts, but says that her own gender identity has not been challenged by her experience with cancer. Rather, Felicia’s feminine identity has changed as she has been able to distance herself from that definition. She continued, “Going through something like this helps you, especially if you hadn’t felt that way before, helps you to recognize how much more there is to you than just your boobs or just your hair. You’re not only your boobs or your hair so. Even with those things gone you can still be you.” Felicia noted that she had to come to terms with the fact that her breasts did not have much value to her beyond the value that society had always placed on them. While it took some time to disconnect that society said was important and what she knew was important about herself, Felicia ultimately felt more confident in her gender identity.

Similarly, Judy, a 69-year-old breast cancer survivor, stated,

I think I feel like I’m stronger than I thought... It’s just a piece of your body I mean if you lost an arm would you feel really I guess you would feel somewhat diminished but it strikes at your femininity I think is the problem. You think because to me; I was thinking well I just won’t feel very womanly without breasts. It just hasn’t changed my feeling that much like I thought it would. I think it’s been really—I feel like I’m a stronger person than I knew I was which is always good to know. (emphasis added)

Judy assumed that losing a breast would affect her feminine identity, but going through the process has helped her realize that her own feminine identity is not defined by these limited cultural definitions. She continued,

I thought it would be really weird not to have breasts, like especially, I mean I guess guys have things that threaten them but for a woman, a lot of your femininity is your breasts. It's kind of what sets you apart in a way. It hasn't really—I don't think I feel different. It's just amazing. I don't know why—it's nice.

This quote exemplifies the point that while these women draw on the cultural conception of femininity as defined by breasts, many of the female patients who I interviewed are adamant that their own femininity remains secure despite the loss of that part of their body. Similar to the male survivors who connect masculinity with sexual function yet argue that their masculinity is intact, these female survivors define femininity by appearance but are clear that they have retained their own feminine identity.

Denise, a 56-year old ovarian cancer survivor, connected femininity with body image throughout the interview and argued that her own feminine identity has not been altered. She says, “I really still feel like a woman, it didn't change anything, you know I—I have the same body and the same soul. You know, it's funny I didn't feel like less of a woman because my uterus and ovaries are gone. I feel—I feel the same.” Judy and Denise are both surprised that the changes to their bodies have not affected them as much as they thought. Judy laughs that she does not feel less feminine because of the loss of her breasts, even though breasts are such a huge part of one's femininity. Similarly, Elizabeth, 60-year-old breast cancer survivor, “It's funny; my reaction is I'm still the same person. So I don't know that it affected my femininity and it wouldn't change my gender, so I'm still a woman. So that seems like to me it's like a non-issue, I guess you would say.” Judy, Denise, and Elizabeth are all surprised that they did not feel like their own gender identity had been impacted. They continue to note that they are still the same

person, even without their breasts. Like Felicia who said she was more than just her hair and boobs, these women note that *they* are not defined by their breasts, even though they still conflate femininity with breasts and physical appearance.

Cynthia, a 48-year-old woman who had undergone a mastectomy, discussed how she thought losing her breast would affect her, but ultimately, she was more amazed by the changes to her body. When I asked her how her femininity had been affected, she responded:

I was like amazed. Because I looked nothing like I looked before, because again, you know when—I mean my boobs were such a huge part of me, so that’s all I saw, that’s like the focal point, and then they weren’t there, and there was no nipple or—I mean I was suddenly so different looking, but I wasn’t like horrified at all, I was just kind of like amazed that they could do, like they can just alter you so dramatically and yet you’re still alive, you know. *Yeah no—none of the sense of loss that a lot of people say that they felt at all, just kind of awed by it.* (emphasis added)

Even though Cynthia acknowledges that her body looked very different, she was clear that she did not feel damaged as a consequence of these changes, like she had heard from others. And when we talked more about sexual intimacy, she made it clear that having new boyfriends see her breasts was a non-issue. While she acknowledged that other women might have concerns over being sexually attractive, she immediately said, “No,” that she did not feel similarly. She continued,

It’s funny because I have had a couple— a couple boyfriends in the last year, and you know I—obviously you don’t talk about it initially, but then I like need to talk about it, because I’m feeling like if we’re going to at any point go in a particular direction, you need to know that there’s going to be—and that’s why they’re called my Humpty Dumpty tits, I mean I’m like ragging. I’ve certainly been intimate with them and they just—it’s such a nonissue. I mean it’s just—it’s zero issue.

When I asked Linda, a 74-year-old breast cancer survivor, “how do you think this experience changed your view of yourself as a woman, or your perceptions of your femininity?” She responded, “Oh, not at all. Not at all, no. That’s not where it is.” She continued to talk

about how some people might have issues with the loss of a breast, but that was not how she felt.

It had nothing to do with the breast surgery. And I can remember being just totally disgusted and horrified with an acquaintance, a man that we knew, after he expressed horror over the fact that you might have to have your breast taken off with breast cancer. And I was so—I was so turned off by him and that, and the attitude.

And I know that it does exist, I've heard some things of that nature and certainly a person's wonderful characteristics aren't physical like that, I don't think. Yeah, so I think you know that's just—but it might have helped to know, for knowing my mom and my mother-in-law, you know both had had mastectomies, and I used to come down with my mother-in-law and go to Nordstrom's and get a new prosthesis, you know she's just get the little gel thing she's put in her bra.

My mom didn't do anything—that would have helped maybe. She just felt so comfortable that she'd climb in her hot tub in Napa, you know with no clothes on, just showing her little incision, you know.

Linda's experiences with her mother and mother-in-law who had had mastectomies might have changed her attitude about the relationship between her own gender identity and the appearance of her breasts, but many other women felt similarly who did not have the same experiences growing up.

Laura, a 50-year-old ovarian cancer survivor, responded, “You know I don't think it affected any of it. You know I don't think I really thought much of that.” And when I followed up about how some women expressed concern over the changes to their body, she stated, “the scars, I have so many of them. You know I was—I'd always told, you know, people that if I ever got to have the body to wear a bikini again that I would probably show all my scars and because that just is a reminder, you know, of and like my battle wounds, you know. It's like I have so many now, you know, and they're not pretty but, you know, they're mine. I earned them.”

Coming to terms with the fact that who you are as a woman was not only about your hair, your

boobs, or your appearance of your bodies helped women cope with these changes. The changes to women's bodies did not impact their own gender identity as they expected.

Women feel more secure with their feminine identity, regardless of what shape their bodies take, even though they still identify with the image-centric understanding of femininity. Shirley, who was 66 at the time of our interview and had undergone both a hysterectomy and bilateral mastectomy, consistently said that her feminine identity was not affected. When discussing her hysterectomy, she said her femininity was “not at all” affected. She continued, “didn't like what was in there anyway. I got my period at nine years of age it was always an annoyance to me. It just made my whole life better. Physically, emotionally, mentally my whole life was better for getting rid of it.” And when we discussed her mastectomy, she said, “No, no my boobs are more beautiful than they ever were. They stand out; they'll never fall down; I never have to wear a bra. I don't have to worry about gravity. No thank God, thank you God.” Shirley connected femininity definitions surrounding physical presentation of her body and her breasts, but was clear that her hysterectomy and her mastectomy were fulfilling to her femininity and not damaging. She finished, “I'm a hot little mama. I have no worries about my femininity. I work hard on my body. I mean I eat right; I work hard; I keep myself attractive; I dress well. No that's just not an issue for me.” While many of these women say that their feminine identity has not changed much, they continue to conflate the broader cultural notion of femininity with appearance: the ability to turn heads and be sexually appealing.

Just as the majority of the women I spoke with connect the broader cultural concept of femininity with a feminine appearance, Nancy, a 71-year-old ovarian cancer survivor, connected femininity with looking nice yet argued that cancer has not affected her own feminine identity. “I don't think about it very much. I still want my hair to look nice and wear a little makeup and not

go out of the house looking that bad, but you know I think I've always been like that, so I don't think it's changed for me." However, Nancy continued to talk about the difficulty that she thinks younger women with ovarian cancer face: "I think I've worked with two 22-year-old women that have gone through this, they're having a rough time, you know, they can't have children, and so I think that question will be big time with younger women." Nancy is one of the few women who directly connected femininity with fertility. Even though she was past childbearing age when she was diagnosed with ovarian cancer, she was quick to mention that younger women might face issues with femininity and the inability to bear children.

However, most women ignored discussions of fertility when discussing femininity. Both ovarian cancer patients and breast cancer patients face issues with reproduction, but they may not connect fertility with their own feminine identity because these cancers are most often diagnosed in post-menopausal women. However, this experience was very real for Jennifer, a 44-year-old ovarian cancer patient who had to have a hysterectomy about a year before our interview. When I asked Jennifer the same question that I asked all of the other respondents, she noted that the loss of fertility has been quite damaging to her sense of femininity:

Yeah, it definitely has affected my perceptions. I mean if someone saw me you know here or out in the street, no one would know that all of this happened, you know my hair never completely fell out, so I still have it, but knowing that your femininity, *your reproductive organs, all of that was taken away from you, it does. You feel kind of inadequate.* And I feel like I am processing that in my therapy, but in the very beginning I was really distraught by that. I just felt like I'm not—*I don't have fertility, I can't ever produce children, I don't even have my reproductive organs, like you just felt like not as feminine.* So it's something I'm still working on. I am in a relationship now, and so it's—it's something that it is hard to get used to, you know and even though the other person doesn't say—it doesn't bother them, and that I'm just as feminine and that it's not something that you know they even think about, I think about it. You know for me it's still an issue. (emphasis added)

Jennifer is one of the few people who I interviewed who was pre-menopausal when she was diagnosed, and one of the only women to connect femininity with childbearing. The inability to produce children made Jennifer feel inadequate as a woman. Jennifer also directly contradicts the oncologists who mention that gynecological cancer patients do not face issues with femininity like breast cancer patients do because you cannot see a hysterectomy. While her focus on the loss of her female reproductive organs is unique, a handful mentioned infertility.

For example, Betty, an 80-year-old ovarian cancer survivor, had a hysterectomy at a much younger age. As a consequence, Betty never had children.

Well, yeah that's you know once you lose those hormones your libido disappears. In that regard that's not good. But I never felt that I was not feminine. *Some people's perception of femininity is that you've got to have kids and that but, unfortunately, no, I never had kids because I had the hysterectomy when I was 36 and never married.* In a way, I'm glad I didn't have kids but still then when you get older you think I might like to have somebody take care of me. That's actually more a concern than the cancer is—what happens when I get older. Hopefully, I'll keep my mind and who knows. (emphasis added)

Betty also linked the cultural notion of femininity to libido, which was uncommon among my interviews, even though she noted that she has not had any issues with her personal feelings of femininity. However, she noted that other people might define femininity as being a mother, something that was never in the cards for her. Betty did not connect feelings of inadequacy to her infertility like Jennifer did, but Betty was among the few to tie femininity to fertility.

Women claim that their own feminine identity is fine, while revealing their assumptions about what femininity is. With few exceptions, my respondents understand femininity as being sexy and looking appropriately female for their predominantly male partners. Given this, most of my respondents define femininity in relation to the male gaze. For these oncologists and patients, being feminine is turning head when you walk into a room and thinking about whether men will still want to sleep with you if you have surgical scars. Women define femininity in relationship

to looking sexually appealing but maintain that their own sense of femininity has been unaffected.

CONCLUSION

Relying on cultural definitions of masculinity and femininity survivors and oncologists define them in very limited terms, almost exclusively focusing on one aspect: masculinity as sexual function and potency for men and femininity as *looking* feminine for their [male] counterparts. Being a man is then conflated with the ability to maintain an active sex life and hold an erection and being a woman is conflated with being attractive. Broader definitions surrounding gender roles and gender performance—such as being able to have or take care of children, go to work, drive, clean, cook, etc.—are entirely ignored.

When I asked about masculinity doctors jump straight to discussions about potency, focusing predominantly on prostate cancer patients given the possibility of sexual side effects for them. Conversations about other ways that cancer may affect men's masculinity were sparse. Similarly, male survivors' of testicular and prostate cancer also connected masculinity to sex. Surprisingly, though most of them argued that *their* identity was not linked to their ability to have sex. As you will see in Chapter 4, I argue that committed relationships play a vital role in helping men disconnect cultural expectations about masculinity from their own identity.

Just as oncologists jump to discussions about masculinity for men, they jump to women's appearance and women's desires to attract men when discussing femininity. Even oncologists who do not work with breast cancer patients assume that breast cancer patients have issues with their own femininity because of the damage to their appearance. Just like the doctors, women who have been diagnosed with breast cancer and gynecological cancer define femininity to looking feminine. Yet, only small minority of the women I interviewed actually claimed that

their own identity was connected to their appearance. Like men, I will show in Chapter 4 that relationships play a key role in explaining this difference.

While survivors' definitions of masculinity and femininity are tied to gendered bodies, bodies ultimately do not become the centerpiece of men's and women's own understandings of them themselves. Therefore, as you will see in the rest of the dissertation, cancer and the disruption to their gendered bodies does not necessarily damage men's and women's gender identity in the ways that we would expect.

CHAPTER 4: MASCULINITY, FEMININITY, AND THE ROLE OF RELATIONSHIPS

I interviewed Karen in her home one afternoon. Karen is a 65-year-old retired social worker who is divorced and has two adult children. She spent her early career as a therapist and the last years of her career as the executive director of a non-profit that she built from the ground up. She spoke about her career with a lot of pride, and it was evident that she invested a lot of herself into this organization. Karen told me, “I loved my career. I was proud of what I did—always got an incredible amount of satisfaction out of it.” After making her mark on the non-profit, Karen retired at the age of 63 and was diagnosed with breast cancer 35 days later.

Karen received her diagnosis after finding a lump during a mammogram. “It had only been one year since I had a mammogram, one day off from one year. And in that one year this lump had developed.” Thirty days after her mammogram and biopsy, Karen had her first lumpectomy. Following her lumpectomy, she was informed that the margins were not clear and there may still be cancer in the breast and they would need to do an additional surgery. “But after that first lumpectomy, you know, I still was totally on the optimistic side. I think that’s why that second one just totally floored me, you know. I was in shock, really truly in shock. Never, ever in a million years expected, you know, I expected them to say we still didn’t get as big a margin as we wanted.”

After the second surgery, Karen’s surgeon called her to give her the results. “So the surgeon calls me and she just said, ‘well we took out 5.4 centimeters of tissue and you’re going to have to have a mastectomy.’ I almost fell out of my chair. I had never considered a mastectomy.” Karen was originally told that she would need one lumpectomy. However, six weeks and two surgeries later, Karen had to face a full mastectomy and a year of chemotherapy.

But for me it felt like it was going from oh you're just going to have a little lumpectomy and, you know, like my other girlfriend had had a lumpectomy and they put a little radiation pellet into the opening and that's all she did and then it's all over and that was years ago and her boob looks the same and I was like you can't tell anything ever happened there. So I went from thinking that was me to finding out that no, it's invasive... It's growing fast and it could be repetitive and therefore you're going to have this drug for a year, you know, in drug infusion in the infusion center.

I felt like little chips were falling, you know, like it went from—and maybe it's partly that the people, the medical professionals, they're passing this information to you, also want to give you good news and want to think the best and so on.

I felt like I had been led down some primrose path and not really honestly told that these things happen to a certain number of people, you know, if this happens do this or, you know, or any kind of other than just kind of it won't happen, it doesn't happen to most people. And you know naturally I think patients, yeah maybe they want to believe it's not going to happen, but for me it was not helpful because it really kind of messed with my confidence and them as advisors where I really—not only did I feel like they didn't coordinate or talk to each other which left me kind of high and dry, but I also felt like they misled me and kind of they were the ones looking through rose colored glasses, not me, you know. And I resented it, you know.

In addition to coming to terms with her aggressive cancer, Karen struggled to come to terms with the loss of her breast. “I liked my breasts, you know, I wasn't interested in the least to cut one off.”

I even joked with [the surgeon], you know, I said you know what, I go before all this happened, you know, I've seen pictures and I've spent lots of time in gym locker rooms and everything and, you know, I may be older now I go but, you know, *I always liked my breasts*. I go as a matter of fact I think *they are kind of Playboy bunny breasts and I feel really bad about losing one of them*. And I go but if I have to I have to and, you know, so we laughed about that, and she had kind of looked at me and says yeah, you know what, I've seen a lot of breasts too and they really are pretty good looking breasts. (emphasis added)

“Losing a breast had a big impact on me.” Karen continued to tell me how she had developed large breasts at a young age and often got a lot of unwanted attention (both positive and

negative).²⁶ As a consequence, she had a strong connection to her breasts as a part of her femininity and struggled to deal with these changes, particularly as a single woman hoping to date after retirement.

And so you know I guess I, you know, when I looked at myself and like I was saying earlier, the lumpectomies didn't do that much, you know, mutilations. A couple of scars, I can deal with that. But the whole like lopsidedness, you know, I don't like it. I'm not happy about it. I knew the one choice was to have a double mastectomy, maybe not even to have reconstruction. And it's too much a part of my femininity and my view and my self-image to do that.

So you know obviously I consider breasts to be part of my femininity and my appeal and feeling attractive to men, and I think that's magnified because I'm single and I'm kind of a 100 percent in person. I promised the people I worked with that when I retired I would really date seriously. I would put energy into that because they're always like "you're this, you're that, you're whatever, why don't you have a partner." And I'd be going, "I don't know because I haven't put any effort into it." And so, you know, I may get back. I mean even my kids are like, "mom, why don't you date?"...

Anyway, so my point being that I don't feel like the woman I was before and I may never feel that way again. I don't know. You know it depends kind of on I think how the plastic surgery works out, you know. I mean I know I'll look fine in clothes and all that, but I know it will strike fear, you know, in regards to an intimate relationship. I just know myself and I know that's true. So we'll see. I don't know. Hopefully I can get past that... I look in the mirror and I never expect to look the same again no matter what they do with plastic surgery or an implant. (emphasis added)

Karen's struggle with her femininity is heightened by the fact that she is single, and she worries what new partners might think about her uneven breasts. She talked about feeling uncomfortable hugging men she meets on dates because they might feel that her breasts are different. Karen continuously emphasized that she does not feel as attractive or as womanly as she used to. Karen always connected her concern about her femininity, self-image, and breasts to being single and feeling pressure to find a new partner. She even noted that her married friends were less concerned about the changes to their bodies.

²⁶ And told a brief yet traumatic story of having her breast grabbed by a stranger on the street at the age of 14.

I'm a single woman, you know, and I do date on occasion. And so I'm not—all my friends that have had breast cancer are married and they have a husband who is there for them and loves them and is, you know, seen them through this and was there before and is there after and the fact that their body now doesn't look the same, they're dealing with it. I don't know the intimate details but, you know, they're still there, you know.

For me I'm like what if I meet some guy that I really like, you know. It's awkward, you know, it's different than being a married woman and I feel mutilated, deformed, whatever word, and so I think what will it be like to confront that, you know. And I think, you know, surviving cancer—it's like there is some stigma to it. It's like will other people that I meet, men and women, think of me as someone who is fragile or who is healthy right now but might not stay that way or, you know, or will they not even think about that stuff. I don't know, but I'm aware of it. I'm conscious of it being another element in my social life, in my relationship to other people.

Karen feels like she is deformed because of the loss of her breast, but these emotions are heightened as a single woman. Her impression is that her married friends are better able to deal with the changes to their bodies because they have the support of their husbands. In addition to issues of self-confidence and femininity, her married friends had the support of their husbands throughout their cancer experience, and she has to worry about what new partners will think or assume about her health.

Karen's description of her concerns about her gender identity and dating were similar to the stories of other single respondents, both men and women. However, a majority of the individuals I interviewed were married, which is consistent with national averages. Eighty-seven percent of Americans baby boomers have been married, and 53% of them are still married to their first partner (Aughinbaugh et al. 2013). So while Karen's experience is similar to the experience of other single individuals, her description stood out against most of the other respondents.

I also interviewed Terry, a 63-year-old man, in his living room. Terry had served in the Navy and is now retired from his career as an accountant. He and his wife of 40 years have two

adult children and one grandchild. Terry's father had been diagnosed with prostate cancer and was treated with radiation therapy. He died at 85 years old, but not from prostate cancer. This family history has made Terry relatively knowledgeable about a prostate cancer diagnosis and his treatment options. Terry was diagnosed with prostate cancer three months prior to our interview, and he and his wife decided to have the robotic surgery and have his prostate removed. His wife, a retired nurse, was actively involved in the decision-making process. "She just said 'let's deal with it.' Nurses are kind of tough, you know. So she said 'let's deal with it.'" After his surgery, Terry wore diapers just to be safe when he went out in public because he was worried about incontinence. However, he never experienced any issues and was no longer wearing anything for precaution.

When making his decision between radiation or surgery, Terry was less concerned with the side effects and more concerned with just getting his cancer out of his body. He felt like his radiologist kept emphasizing that he would be impotent with surgery, but Terry felt more comfortable with the surgeon and really just wanted to get it out.

And I mean we're older anyway so—and my wife is good with it [being impotent]. She goes, you know, I just want you around. But when we came out with the radiologist—and they give you like a questionnaire and it's more geared to sex, and like I mean our sex life was great before so I think they gear it towards that. But it seemed like it was more like it came down to the sex part, like with radiation. But I just wanted it—basically I wanted it—my mind wanted it out of my body.

When I asked Terry about the changes to his masculinity, he responded, "Didn't change. I mean I did think about the erections and all but it didn't really—when my wife goes hey, I just want you. You do think about it a little bit but I think everything is going to be good." Terry's partner eased his concerns by telling him that she just wanted him and was not concerned about the loss of erections. He continued to tell me that immediately following his surgery, his wife took up the task of doing research on how to improve potency. "Yeah, my wife goes, 'I'll take over that

part.’ She said she’ll be the keenest rehabilitator.” And even though he was originally hesitant to start her “rehab” to get the blood flowing back to his penis following the removal of his catheter post-surgery, he now enjoys that his wife’s approach to his impotence: “So and my wife is taking that [solving my impotence] as a challenge. You can’t beat that, right?” Terry relied on his wife a lot throughout his experience with cancer. They decided together that potency was their last priority and that his survival was the primary concern. Terry credits his wife for the fact that he does not feel emasculated through this process.

Relationships are key in helping my respondents come to terms with changes to their bodies. Single men expressed greater concerns about their masculinity, while married men credited their spouses for their lack of concern. The same holds true for women.

As I explained in Chapter 3, most of the people I interviewed argued that they did not experience the damage to their masculinity or femininity that they had expected. Sixty-six percent of the individuals I interviewed were married at the time of our interview, and a much larger percentage of my older respondents were married—consistent with national averages. In this chapter, I argue that being in a committed relationship plays a key role in reducing the feelings of insecurity surrounding sexual function for men and physical appearance for women. Single men and women, such as Karen, expressed more concerns about their own gender identity.

Relationships, and the lack thereof, are particularly important when men and women think how much their masculinity (as they define by their sexual function) or femininity (as they define by their appearance) affects their sense of self. While scholars have long argued that marriage is a sexist and patriarchal structure that reinforces gender essentialist beliefs and subsequent inequality and the oppression of women (Brooks 2002; Ridgeway 2011; Willis

1984), in this case, I argue that marriage is the very thing that allows survivors to move away from the sexist and patriarchal cultural schemas surrounding masculinity and femininity. Both men and women in relationships are able to challenge hegemonic understandings of their gender identity. In this chapter, I explore the role of relationships in alleviating the damage to their gender identity that we would expect given the literature on cancer survivors.

First, I look at how single men and women talk about their masculine and feminine identity. Like Karen, single men and women feel a greater loss to their own identity as a consequence of not being in a committed marital relationship. Second, I explore how married men and women discuss the changes to their gender identity. Time and time again, married individuals point to their spouse as the key reason why they feel secure with the changes that they experienced as a result of their cancer.

BEING SINGLE

When mentioning concerns about the changes to their masculinity and femininity, respondents frequently discussed their relationships and relationship status. Single men and women (those not in committed *marital* relationships) are more impacted by the changes in their sexual function and feminine appearance, respectively. Even if respondents are in a relationship, if they are not married or engaged, they feel more insecure about their gender identity than their married or engaged counterparts. In the following section, I will first show how single men feel emasculated because of the changes to their potency. I will then show how single women feel more concerned about their new appearance.

“Single” Men and Insecurity

As shown previously, men define masculinity by sexuality. Therefore, many single men and men in new relationships²⁷ face more feelings of insecurity and emasculation due to their lack of committed partnership. “Single” men feel greater concern about the changes to their sexual function. They were more open talking about feeling emasculated, and many of them fear that their loss of potency and virility might affect their chances of finding or keeping a new mate. This is true for Thomas, who struggles with emasculation because of the loss of his sexual function. Thomas is a 75-year-old retired lawyer, who described himself as “always single” with no kids. While he had never been married and was not in a sexual relationship at the time of the interview, he discussed feeling very emasculated because he could not engage in sexual activity. When I asked Thomas, “How do you think cancer has changed your view of yourself as a man or your perceptions of your masculinity?” he replied,

Well you know you may be opening a door there. *One of the sad things about getting old and when you say masculinity, to me, I don't have a wife, I don't have a social life to tell, I don't have a sexual life either and that is sorta sad because I like to feel that I still have some youth in me. Other guys seems to be a little bit more relaxed about it, I'd like to have sex every day but I can't.* I mean I couldn't even if it was available to me and not having sex every—regularly, on a regular basis is a problem I have to wrestle with. It's been that way for a longer time than I wished. And so if you say masculine, to me, to feel like a man is to have sex regularly with a woman, you know. I don't know, but I—it seems like a lot of men just grow and develop right into that it's okay, well it ain't okay with me because I still have youthful feelings and I still wanna have—mix it up... So if I'm answering your question, how do I feel about my masculinity, that is a concern of mine. (emphasis added)

Thomas chose to move forward with radiation instead of surgery in hopes of preserving some of his sexual function. He noted that his choice of treatment was based solely on his concerns about side effects.

The sexual part is—yeah, sure, I have some mechanical problems you might say,

²⁷ Moving forward, I will use the word single to indicate individuals who were not married or engaged. Even though some of these men were in relationships, they still occasionally referred to themselves as single and were more similar to the single men than the married men.

you know? Having a normal sex relationship that is having—you know, I’m not a kid anymore either, even without prostate cancer I could have that inability to get an erection strong enough for penetration. So that is—all men are deadly aware and afraid of that. And—but as you know—you don’t, when you’re in your mid-70s males, they can’t get it up anymore anyway, it’s pretty—so yeah, that was a concern of mine.

While he understands that he likely would still have mechanical issues because he is in his 70s, Thomas struggles to grapple with the loss of sexual prowess while being single. His concern is great enough that he takes testosterone to help with erection issues (even though many of his doctors advice against this).²⁸ Thomas was clear throughout the interview that sexual function was a primary concern, especially as a single man. He noted that many of the other men in his support group have come to terms with losing their potency but that it is still a large issue for him.

Similarly, Larry feels emasculated and castrated because of the loss of his libido, especially as a “single man” with a girlfriend. Larry noted that he would not blame his girlfriend for leaving him because he can no longer perform as well as he used to. When asked about his masculinity, Larry responded:

I used to talk about developing sensitivity, massage, and drop of water from an ice cube on your skin can bring a chilling reaction in the right circumstance to be a turn on. I was very good at those types of subtle things. That manhood is gone and the desire to do those things is now manufactured—it’s remembered, not spontaneous. It would be difficult to go out and find a new partner because I am “single.” I’m not going to, but I’d understand if she wanted to leave because there’s no future with me. It would be difficult to establish with a woman because I don’t have that sexuality any more. So castration, and I think this is what you’re getting at, is castration is taking away how I relate to women.

Larry noted that it would be difficult to establish a new relationship because he does not have the same sexuality that he did before. His feels castrated, as if his manhood is gone.

²⁸ Refer to Chapter 6 to read more about testosterone and the role of biomedical technology.

The topic of castration came up repeatedly among single men. Kenneth, a 66 year old divorcee with 3 adult children, said that after his surgery, “I feel, you know, somewhat like [I’m] going through a sex change.” When I inquired about his perception of his masculinity, Kenneth answered, “You know it’s a neutering process. I’m still in process. So I think I’ve recovered already up to this point just in terms of feeling somewhat emasculated and—and unable to you know be a male in the full sense of the word as a partner.” Kenneth was in a newer relationship with his girlfriend and was concerned that his potency issues may affect that relationship.

When I asked whether he would feel different if he were not in a relationship, Kenneth continued, “I worry as much for her as I do—I mean I worry for our relationship and the potential destabilization of that or changes that that brings. So yeah, that’s a big—that’s a big factor.” Like Larry, Kenneth was in a relatively new relationship and felt uneasy about not being able to perform sexually for his female partner. Kenneth made it quite clear that the chance that he could have decreased sexual function would be reason enough for his girlfriend to leave him.

When weighing his options for treatment, he mentioned his concerns about impotence:

Because of the side effects, sure. I mean, I told her—I told—I said, you have every right to—I need to be open with you and she already knew it, but you have every right to leave me. You know, you have the right to a healthy sex life with a loving partner and if I can’t provide that then you need to—you have every right to do that.

Kenneth felt like there would be less pressure for intimacy if he was not in a new relationship, and he feared that his impotence might lead to the demise of their relationship. Because these prostate cancer survivors feared that the loss of potency would ruin their new relationships, they expressed greater concerns about changes to their masculinity.

Single men with testicular cancer shared similar sentiments to their older counterparts.

When asked how he felt about the changes to his body, Kevin, a 39-year-old testicular cancer survivor, said:

I don't like it at all. I don't like it at all. But I am alive and I understand this had to be a part of it, and for me to be alive then I'll deal with that. That [the loss of a testicle] is an ego buster, I'll tell you that. It really is, you know. I feel I've lost some of my confidence in myself. *You know when you go to a bar, talking to women or whatever, just generally in talking to women* it's just like I have no interest at the moment and I know that's part of the reason, you know, is because you're a little different now, you know. (emphasis added)

Kevin feels that he has lost some his confidence with the loss of his testicle, and as a single man, he now has more fears talking to women.

Another single testicular cancer survivor, 23-year-old Nicholas, thinks that if he had been older and married, he would not feel as insecure about the changes to his body.

I was single when I had the testicle removed. If I hadn't been at that time I might have been more concerned about it, just that it would change the way that I look and all that. It might have. And then I did have a girlfriend at the time of the major surgery and the chemo and I don't think it changed too much except for I didn't want her to see me like that, like I was actually worried and which was why it was kind of bad that she was around so much. *I think it would have been a lot different if maybe I'd been older and had actually been married for a few years or something.* I feel like it probably would have been better just in terms of having a support there and everything and *not having to worry about once this is over how in the world do I go about dating and how in the world would I go about, you know, all this stuff and the worry of having children,* like if I had children prior to it, you know, the infertility probably wouldn't bother me as much as it does now. I don't know. I've read about several men who had testicular cancer and had been married and had kids and everything. And they don't really talk about those issues that I do about that infertility and all that. It doesn't seem to bother them as much. (emphasis added)

Nicholas observed that married men and men with families do not seem to express the same concerns that he has about masculinity and fertility. Nicholas believes that partners provide support that single individuals do not have. He worries about dating, now that his body looks the

way it does. Nicholas is also particularly concerned about his fertility, which I will discuss in more depth in Chapter 6.

Among testicular cancer and prostate cancer patients, single men were more likely to express concerns about their masculine identity. This is not entirely surprising, given that masculinity is culturally defined as potency and sexual function, both very important in relationships. However, single men were a minority in my sample. Most of the men I spoke with argued that their masculinity has not been damaged, pointing to their relationship as the most important factor in preventing these feelings. Similar to the single men, single women expressed greater concerns about their femininity.

“Single” Women and Insecurity

Relying on cultural definitions of femininity surrounding sex appeal and appearance, single women face more insecurity about the changes to their gendered bodies than do their married counterparts. Like Karen, single women emphasize the need to be physically attractive to meet and entice new partners. As a consequence, their gender identity becomes more connected to their physical features and they felt more damaged than married women as a result of the changes to their gendered body. In interviews, single women were more likely to express feeling a loss in relationship to their femininity.

Cynthia, a single 48-year-old breast cancer survivor, decided to have reconstructive surgery because she wanted her body to be normative when she gets back out dating. Later Cynthia mentioned that she would not have felt obligated to have reconstruction if she were in married or in a committed relationship. “Well I’d probably—well, I obviously would have asked that person what they thought. You know I wouldn’t have felt as compelled a need to

do that.” For Cynthia, the desire to attract a new partner at some point meant that she needed to have a body that matched normal expectations.²⁹

Shirley, who is a single grandmother at 66 years old and has had a hysterectomy due to ovarian cancer and a prophylactic mastectomy when she found out she was BRCA+, explained to my why she personally thinks people choose not to have breast reconstruction:

Okay. Well, I’ll tell you why they do it and why they don’t do it as I understand it personally. It basically again for me it’s a vanity thing I work this body hard, and I show it off. I love to dress and that’s just who I am so, of course; I wanted to have a shape that looked like a shape. The women who don’t do it don’t do it for one of two reasons; they’re either very sports involved; they’re rowers, tennis players, etcetera, and it gets in the way. They worry about lymphedema and just some muscle stretching, etcetera. Then there are other women who simply don’t want to go through the process. They’re happy in their marriages and lives and whatever. It’s not an issue for their husband, I think a husband’s opinion is a very high criteria. Every one of those women’s husbands could not have cared less whether they had boobs or not. I don’t know any woman whose husband wanted her to keep it, and she didn’t want to keep it and did or did not.

Shirley decided to have breast reconstruction on account of her “vanity.” She claimed that the women who decide against reconstruction either have physical reasons or are married with husbands who will remain committed despite their partners’ bodily changes and appearance.

Shirley was quick to note that a solid marriage helps women deal with vanity issues and is a key reason why women choose not to have reconstruction. While Shirley still feels like a “hot little mama,” she attributes a lot of her security to her decision to have reconstruction, which was in turn heavily influenced by her being single.

Jennifer, the single woman who was 44 when she had a complete hysterectomy, feels less feminine because of the changes to her body and loss of female reproductive organs. Recall from Chapter 3 that she was one of the few pre-menopausal women who had been diagnosed with

²⁹ Cynthia was less insecure than many of the other single women and while she felt obligated to fix her breasts to be competitive on the dating scene, she made it clear that when she did date most guys did not actually care that her breasts were scarred. Cynthia’s decision to undergo breast reconstruction is expanded more in Chapter 6.

ovarian cancer. Jennifer's inability to bear children and the removal of her reproductive organs made her feel inadequate and less feminine. At the time of our interview, Jennifer was currently dating someone, but she still feels uncomfortable, especially given the nature of a newer relationship.

I am in a relationship now, and so it's—it's something that it is hard to get used to, you know and even though the other person says it doesn't bother them, and that I'm just as feminine and that it's not something that you know they even think about, I think about it. You know for me it's still an issue, yeah.

Briefly recap how being single makes Jennifer not only feel insecure about her hysterectomy, but that lack of security about her internal organs also negatively impacts her feminine identity. Therefore, dating became more difficult for Jennifer and the other single women after their treatment. These women felt less secure about their appearance, which is emphasized on the dating scene.

Single individuals also feel a lack of intimacy and social support. Barbara, a 74-year-old ovarian cancer survivor, talked longingly about the ways that many women's husbands supported them throughout the process, something that she will never experience as an older single woman.

I think I would feel a lot different. I think that if I had—I look at these women and their wonderful husbands, I wrote something, like a little tribute to them, because they—there are a couple of guys that come to all the meetings, they go to—we go to conferences and things to learn—keep up on the research and these men go along with them, and they all have—some of them have jobs and have serious careers but they make their wife's medical situation primary. They do research on all of the—everything that's available, and they just support them in so many ways. And I think it's beautiful, it's really wonderful. And you know I feel bad that I don't have that, and I'll never have it, you know. I like looking at old people walking around holding hands, and I look at it, and I think I'll never have that 50-year marriage.

Barbara recalled other women's husbands attending support groups, and she heard stories of them going to doctor's appointments with their partners and prioritizing their wives over their

careers. Barbara feels bad that she does not have the same type of support. Besides the support, Barbara feels like she missed a lot of intimacy because she was not in a long-term relationship.

Well the whole situation of men and partners and support and sex and all that. Being single, I don't have any of that. And I think that you miss just generally being touched. I mean girlfriends hug and all that, but—so I met this guy but he lives up in Seattle, nice, probably I'll see him a couple times a year or three times a year. So that's not going to—and I could go back and—I mean I actually think that maybe I should get massages or something to—to feel something.

This lack of support and intimacy was challenging for Barbara. While she has a long-distance relationship, it is not able to fulfill her desires for more affection.

Single men and women feel more insecure about the changes to their bodies, a loss of support, and a lack of intimacy. Single men worry that their new partners will have concerns about their sexual function, and single women worry that they will not look attractive enough for their new partners. Not being in a long-term partnership leads people to rely more heavily on hegemonic understandings of masculinity and femininity. These single respondents believe that in order to gain approval from dates and potential partners, their bodies and sexual functions need to closely resemble the hegemonic cultural definitions of masculinity and femininity.

MARRIED/PARTNERED

As I showed in Chapter 3, many men and women argued that their masculinity and femininity had not been damaged as much as they had assumed it would. Even though they were clear that their sexual function and appearance had changed, they do not feel like it had negatively affected them. When people explained that their own gender identity had not changed, most of them jumped straight to their husbands, wives, and fiancés. Committed marital relationships played a key role in explaining why they are not as concerned about the changes to their bodies. Culturally, we expect that our husband or wife should love us regardless of our appearance or sexual function, while new partners may be less attracted or interested. As a

consequence, I argue that marriage is crucial in explaining why most men and women remain secure in their gender identity. In the following section, I argue that marriage (or the likelihood of marriage) helps both men and women disconnect cultural understandings of masculinity and femininity from their *own* sense of self. I will first show how married men argued that their masculinity has not been affected because of their significant other, but they know they would feel different if they were single. I will then discuss how married women similarly argued that their relationships help their body image issues.

Partnered Men and Security

Partnered men recognize that being single would have made their experience much more difficult and argue that their relationships have allowed them to move beyond the cultural definition of masculinity. While they may have been more focused on the loss of their sexual function if they were single, men's partners made them feel more secure with their masculinity. James, a 28-year-old testicular cancer survivor, states that masculinity has not been much of an issue for him. However, he imagines that if he were single, he would feel differently.

It hasn't really changed that much, but I think that's mostly due to me being married. I mean if I was single it probably would change a lot how I felt as a man but my wife hasn't made me feel like less of a man, so I don't. But I'm sure if I was single I probably wouldn't feel that way.

James noted that his wife has not made him feel less like a man, but if he had been single at the time, he would have felt emasculated. Similarly, Ron, a 71-year-old prostate cancer survivor, said that he imagines dating would be much harder, and that single men probably have bigger issues with their masculinity than he does.

Just that—you know having a relationship with a woman if—you know if you're not married you're on the dating scene at that age, it's hard enough, and then when you—you know then you've got issues with sexual issues, and that would make it even harder, *I think it would affect your attitude, as you said, about losing your manliness*. And you wouldn't have the support. (emphasis added)

Like James and Ron, the men in relationships routinely argued that their masculinity would be more damaged if they were single. They expect that single men face different issues.

Like James, Michael, a 53-year-old testicular cancer survivor responded, “Well, I think the fact that I’ve had kids, and I’m not looking to have any more; I’m married, I’m not like dating. I think I’d be a lot more nervous about things if I was single, I’d be a lot more unconfident like just dating. I think I’m really fortunate that I don’t have to deal with that.” For Michael, the idea of being single and having to consider potential concerns about the loss of fertility and his testicle seems far worse.

Relationships allow men to feel secure with the changes to their gendered bodies. Eric, a 42-year-old testicular cancer survivor, noted that his sexuality is secure in his marriage but said that he understands why single men might look into getting a prosthetic testicle:

For me, sexuality was not good up until marriage. So other than I guess discussing it with a potential partner if I were single for me in my circumstances, I don’t think it probably would have made much of a difference. But I can definitely see where in other people they might be more led to consider prosthetics just from a cosmetic standpoint if they were single sure.

Similarly, Joshua, a 29-year-old testicular survivor, argued that his fiancé has helped him deal with the psychological and aesthetic concerns of losing a testicle. Joshua is a bit of an exception because he is the only gay man I interviewed. However, he relies on his committed relationship in similar ways to his straight counterparts.

Just you know, it’s going to fine. Just like you have two kidneys and you can operate with just one, kind of the same thing aesthetically and actually it doesn’t change much at all. And to this day that’s kind of my experience as well. It hasn’t really changed much at all. Makes it easier to cross my legs quickly. And psychologically I think that was also answered really quickly and really well, *especially by my fiancé*. You know so much of, you know, this is my body and it’s changing and it’s going to change pretty quickly, you know, just no doubt that in a few days I won’t have a right testicle anymore. You know having that support from him was important and needed and he said I really don’t care what you have

and what you don't have. So that was important for me from that standpoint.
(emphasis added)

Joshua's partner helped him process the loss of his testicle and deal with issues of masculinity. Joshua's partner saying, "I really don't care what you have and what you don't have," is similar to Terry's description of his wife just wanting him to be around.

Partnered Women and Confidence

Because femininity is culturally defined by appearance, most women had anticipated feeling a loss of self due to the change in their feminine appearance. However, many women remained secure with their self-identity because of their relationships. When I asked married women about the changes to their femininity, many of them mentioned not feeling changes to their femininity because of their husbands. They jumped straight into conversation about looking attractive but were quick to state that their husbands were the sole reason for not feeling insecure. As a consequence, most married women also assumed that being single would make women feel less secure and cause them to have greater issues with their femininity. For example, Tammy, a 51-year-old breast cancer survivor, stated, "I'm not sure that the girls are as pretty as they used to be. There's a little bit of, 'Oh, I have this ugly scar,' but my husband doesn't seem to care. He just doesn't care, so I'm good. I think I might have felt differently [if I were single] because then you don't want to show people your scar." Tammy was clear that her own femininity has not changed, and she is fine with the fact that her "girls" are not the same because of the support of her husband. Tammy and her husband had been together for 18 years, and Tammy fears she might have felt differently if she had to show her body to new partners. Having the security of an 18-year-old marriage helped Tammy feel more confident with her changed body.

Similarly, when I asked Janet, a 55-year-old ovarian cancer survivor, how her femininity had changed, she responded:

No, not at all, not at all, but that's probably because I do have a supportive husband. I mean I think when I was bald I used to kid around with him and say "do you mind making love to a bald woman?" You know. I didn't feel as attractive as he made me feel so I got over that with his help, so no that didn't really stick with me, maybe for a little while it did 'cause not so much that you no longer have your female parts but that you just feel a little ugly, you know... So as far as my femininity that didn't suffer as much as you would think, you know... I mean I guess it would be—it would affect it if I were looking for a man and that I would have to be presenting myself to a man who had never had never seen me naked with scars, you know. But again I've always had a pretty good sense of my body. It's not like I've ever been ashamed of it. So no. (emphasis added)

Janet immediately said that her femininity remained stable because of the support from her husband. While Janet felt unattractive at first, she and her husband of 12 years maintained their intimacy throughout, and her insecurities went away quickly. But like Tammy, Janet imagines that she would have greater issues with her femininity if she were single and looking for a new partner. Married women were quick to mention the role of their husbands when explaining why they do not feel like their own femininity has changed.

Similarly, Brenda, a 62-year-old ovarian cancer survivor, feels more comfortable because of her husband. When I asked about changes to her perception of her femininity, she noted that she would not feel as confident if she were single:

I think if I were not married and comfortable in my marriage, I would probably have a hard time with finding a new mate or wanting to meet a new mate, because of my scarred body. But I don't think I would be closed to it, if the right person came along that made me feel comfortable with him. So I know I'm not talking about me personally, but I guess I pondered that thought like how would I be if it had to start over, because I've met women who aren't married, and they want to meet somebody, so I kind of wondered, I wonder how that would be for me. Would I be able—I feel like I probably wouldn't get remarried. (emphasis added)

Brenda does not feel like she has issues with her femininity but imagines that if she were single things would look differently. Showing her scarred body to a new partner would likely be

uncomfortable, and she is not sure how she would be able to handle this without the support of her husband.

Additionally, when I asked 53-year-old ovarian cancer survivor, Lisa, how this experience changed her perception of her femininity, she immediately jumped to her husband:

I'm very fortunate to have a very loving husband. I think, you know, the feeling of being damaged goods if you were still trying to date and have companions in your life, that would be nasty. I don't feel like damaged goods and I feel like this body has been through a heck of a lot and it's—but I still feel like I value myself and I have value as a woman.

Lisa continued:

Like the woman who said that [she felt like damaged goods] in the support group. Like I think it would be very hard to enter in a new relationship knowing that you have recurring ovarian cancer... There's ease with sexuality that's not possible anymore and I think of that as being kind of the damaged goods stuff. It's just an odd phrase because it feels like it's dehumanizing but it's just so very, very human. And I don't feel like damaged goods, but when she expressed that I realized how it's a helpful thing to be in an established, loving marriage.

Another woman had referred to herself as damaged goods in Lisa's support group, and while Lisa did not herself feel that way, she understood how someone might. For Lisa, her committed husband helped prevent her from feeling injured.

Women routinely acknowledged that their bodies were damaged, changed, or altered, but they consistently argued that this did not affect their own self-image or gender identity because of the support of their husbands. Likewise, 60-year-old breast cancer survivor, Margaret, said that her femininity has not changed despite her lumpectomy. She noted, "It didn't one way or the other. I was worried about dating. What if a guy sees my breast and there's like a lump out of there? But my current husband, he didn't care. It [the changes to my breast] didn't change my idea of my femininity."

Similarly, Sandra, a 64-year-old breast cancer survivor, was afraid that after her surgery she would look different and that it might affect her femininity. Ultimately, she found that because her husband did not care what she looked like and wanted her alive, her fears of looking less feminine went away.

Well, I had—I was afraid that—I mean I was afraid that maybe my decision wasn't right. Even though I felt confident about what my husband and I had decided, I thought well, you know what if I don't like the way I look when I come out of surgery. But my husband kept saying you know I don't care, he said; remember we're doing this for your health. He said, I don't care what you look like out of surgery. So those fears kind of went away.

Sandra's concerns about her femininity and her appearance were assuaged by her husband's reminders.

The significance of relationships came up time and time again as women stated that they were not concerned about their physical appearance but could imagine that if they were single, this would be a bigger issue. Women routinely expected to feel a loss of self and a damaged body image, and they expected other women to also feel these things. However, married women said that they just did not. Married women turned to their husbands and because they felt supported, women were able to feel secure with the changes to their gendered bodies. Similarly, married men's partners made men feel secure with erectile, fertility, or body image issues. This security provides men and women with the opportunity to disconnect their own gender identity from the appearance and function of their body.

EXCEPTIONS

Overall, married men and women claimed that their partners are the reasons why they do not have issues with their masculinity and femininity. I found two exceptions to this: 1) a woman who is happily married and feels supported by her partner but still feels insecure, and 2) a woman whose partner was not emotionally supportive about the changes to her body.

First, there is Carolyn, a 56-year-old breast cancer survivor. Carolyn has an advanced degree and works in a male-dominated field. While Carolyn is certain that she would feel worse if she were single, she still feels damaged and insecure even with the support of her husband. When I asked Carolyn about changes to her femininity, she immediately started to discuss how much harder this would be for single women:

Yeah, you know, and I feel bad for women who are not in a committed relationship at the time they go through this. So my husband's really never been a real verbally demonstrative person and so it's not like we've talked through the fact that you're still beautiful to me or I still love or anything. But you know, actions speak louder than words and so I'm lucky that I still you know, have that closeness with him. But—so if—and again, *it's more on my side I think than his side I guess is what I'm trying to say. So I don't think it is an issue for him but it's an issue for me.* (emphasis added)

Carolyn feels bad for single women. Even though she knows that her husband loves her and his actions towards her have not changed, Carolyn still feels insecure—perhaps because he has not provided verbal affirmations. Carolyn's femininity still feels damaged even though she did not think her appearance was an issue for her husband. She continued:

Yeah, so I don't feel like I'm as attractive as I was before. You know, I don't think that he loves me any less but I just don't—I don't feel as attractive as I did before. And again, I have not—I think maybe it's because being a scientist or whatever in a male-dominated profession, I've always wanted to—like, I've never been one who's worn a lot of makeup or been really concerned about my hairstyle or anything like that or clothes. In fact, I don't want to call attention to myself in that way, I wanna be seen as you know, a professional first. And so in that sense, you know maybe that's helpful for me because now I'm still seen as a professional. And so that hasn't been a big part of my self image in terms of you know, *anything other than really just my relationship with my husband and so that's—but you know, it's—no doubt it's taken a hit for sure.* (emphasis added)

While most married women sounded like Carolyn because they imagined feeling worse if they were single and did not have the support of their husbands, Carolyn still feels like her femininity has taken a hit, whereas more married women argued that their husbands had alleviated their

insecurity. Carolyn stands out as an exception when discussing how she still feels less attractive, even though her husband has been supportive about her appearance.

Denise, a 56-year-old ovarian cancer survivor, is another exception. Denise was married at the time of her diagnosis and maintained that her femininity was not affected. However, her husband was explicitly unsupportive about the changes to her body and her appearance. Denise's husband found her scars unattractive and did not like when she lost her hair. According to Denise, her husband left because of the way she looked. Denise told me a story about her wig party where friends came over and brought wigs and the hairdresser shaved her head. And when I asked Denise about wearing her wig, she continued:

No, at home I would take it off, and seeing my bald head, that's what made my husband leave, and my scar. So the—right after I got my head shaved, he came in and said I have to leave. So he left. It was a good thing. It was a good thing. He was very, very angry and he couldn't get past the anger...

So then when he said you know I've got to leave. It was actually a really good thing, because I can't be around somebody who, you know—who's very negative and angry. And I needed to be around positive people. So him being gone was—was really, really helpful to my recovery.

Denise and her husband had been together for 28 years when she was diagnosed, and he left at the beginning of her treatment. While Denise was clear that she felt good about the fact that he left because she needed positivity in her life to get through her treatment, her husband told her that he was leaving because of the changes to her body. When I asked about her about why she felt like the changes to her body had affected her husband, she said, “well he told me. You know he told me. It made me look sick like I was going to die.” However, Denise feels confident that these changes to her body and her husband's reaction had not affected her sense of self or body image.

Well you know I've had scars before, so it really didn't bother me, you know, I've never been a bikini wearer, you know and I had a little infection at the bottom,

they had to take out of the—or two of the staples so it drained a little while. But I didn't have any trouble with it. It didn't change my body image. When I asked her about changes to her femininity, she said that she still feels like a woman, "I really still feel like a woman, it didn't change anything, you know I—I have the same body and the same soul. You know, it's funny I didn't feel like less of a woman because my uterus and ovaries are gone." However, when I followed up and asked her why she thinks she feels so comfortable, she responded:

Well you know this was something else that my husband really helped me with. I don't think I had a good self-image until he came along. And he—he gave that to me. He helped me feel comfortable with the way that I looked and felt. He, you know, that's funny, I didn't realize that until right now, something else I'm grateful to him.

Being in a married partnership with her ex-husband for 28 years gave Denise confidence. When he withdrew that support, Denise still felt feminine. However, Denise's story about her husband being explicitly unsupportive about her appearance was very uncommon.

Only one married women, Carolyn, stated that she still had femininity issues even though she had a supportive husband, and only one woman, Denise, talked about being secure even with an unsupportive husband. Overall, most married women claimed that they did not have femininity issues and discussed the role of their husbands in alleviating the damage that they assumed they would have faced. The same goes for married men.

CONCLUSION

Because so much of gender identity is created and maintained through social roles in interaction, marriage is a key institution for understanding gender. Identities are altered and reinforced through interactions, therefore, intimate relationships become pivotal in determining gender identities. While marriage as an institution has often been understood as patriarchal because of its role in reinforcing inequity and reproducing beliefs about the naturalness of gender

difference (Brooks 2002; Ridgeway 2011; Willis 1984), I argue that marriage can become a space for individuals to move beyond hegemonic understandings of their own gender.

As shown in Chapter 3, men define masculinity as sexual function and women define femininity as sex appeal. However, most respondents argued that their own identity was not connected to these definitions. In this chapter, I have shown that relationships play a key role in explaining why most men remain secure in their own sense of masculinity even though their sexual function has been impaired by their cancer treatment. In addition, relationships allow women to feel confident about their own femininity even though their physical appearance has been altered.

Single men and women articulated feeling more insecure about their own masculine and feminine identity as they work to attract and satisfy new partners. Single men feel more emasculated than their married counterparts *because* of the lack of a committed relationship. Similarly, single women have more concerns about their appearance. Therefore, single respondents feel more pressure to conform to the requirements of hegemonic masculinity and emphasized femininity.

Married men and women feel more secure about the changes to their sexual function and appearance. When asked about their masculinity and femininity, most married individuals jumped straight to their spouse as the source of their assuredness. Additionally, married men and women were clear that they likely would not feel this self-confident if they were still dating. For married individuals, the idea of the having to attract a new partner with these new bodies seems more difficult and damaging. Therefore, marriage allows men and women to disconnect their own gender identity from hegemonic social definitions of what it means to be a man or a woman.

CHAPTER 5: GENDER, IDENTITY, AND CONTROL

I met Nancy at her home. Nancy is 72 years old, about 5 feet tall, and has a short hair cut with stark white hair. She lovingly described herself as a “Q-Tip,” and she said, “I call it my reward from what I went through.” Nancy is a retired accountant with two adult children and has been with her current husband for 30 years. After Nancy made us coffee, we sat in her kitchen with chairs facing her garden and talked for two hours. She started by explaining how she was diagnosed with ovarian cancer 6 years prior after months of experiencing side effects and being dismissed by her healthcare professionals.³⁰

Once she was seen by physicians and accurately diagnosed, Nancy was immediately hospitalized, given a feeding tube, and started chemotherapy to shrink her tumors and get rid of the massive amount of fluid that had developed. While hospitalized, Nancy decided to name her tumors after people she did not like. “I told them they’d be the size of raisins when I was through with them. And I could honestly, during chemo I could feel stabs of pain, and I’d be yeah, got another one, you know it was like it was killing it.” After months, the tumors shrunk enough so that Nancy could have surgery. Nancy underwent a full hysterectomy and had tumors removed from her bowel, appendix, and stomach. During surgery, her oncologist found cancer “everywhere... He said there was cancer in everything.”

Consequently, Nancy immediately started a very aggressive form of chemotherapy that was administered directly into her abdomen. After a year of chemotherapy, Nancy opted into another year of chemo. Nancy underwent chemotherapy everyday “six, seven hours in the chair,

³⁰ Nancy’s experience of being misdiagnosed is quite common among ovarian cancer patients. Ovarian cancer is sometimes referred to as the “silent killer” because its symptoms can be mild or masked by numerous other issues. A common symptom is swelling and pain in the abdomen—Nancy’s primary symptom. However, medical doctors often try to treat this like bloating. A number of my respondents with ovarian cancer had faced misdiagnosis and now organize a group that teaches medical students and residents about ovarian cancer symptoms. Breast cancer, testicular cancer, and prostate cancer do not face these same issues as frequently as ovarian cancer given the nature of their diagnosis and symptoms.

two years of it.” Nancy told her story very positively, but she recognized that she was on the brink of death when she was diagnosed. Nancy casually mentioned that she was not really “steady” until after her first of year of chemo, 16 months after she noticed symptoms.

Nancy felt like the only way she would survive would be to take complete control, even if it meant acting out of character.

I’m not just aggressive that way. And [the primary care physician] told me, “I want you to see this GI doctor the next day.” I called his office and they say, “we have no appointment for six weeks.” And something came out of my mouth like you—”he needs to see me tomorrow. It’s an emergency.” That was not me. So all of a sudden, I started kind of becoming my own advocate and thank goodness.

When reflecting on her experience undergoing treatment, she expressed gratitude that she survived (especially because so many of her friends from her support groups have passed away) and that she has grown so much because of this experience. Nancy stated, “I have come to actually feel grateful for the cancer, because of what I’ve got now.” She repeatedly talked about her desire to take care of herself and maintain control over her life without feeling bad for herself, even when she thought that she might not be able to survive. “I’m the one and I’ve got to make the choices, and I sure don’t choose to be an invalid or feel sorry for myself, I’ve never ever, even thought ‘why me?’ I would think ‘thank goodness it was me and not somebody I love,’ because I would rather go through it than watch my loved one go through it.” Nancy was very adamant that she could handle whatever was thrown her way even through her most difficult treatments. Throughout the interview, she talked about how much she loved every second of chemo because it was killing her cancer and was happy when her hair fell out because it meant her chemo was working. Naming her tumors after people who had hurt her and envisioning her chemo killing them helped Nancy shape her experience. She maintained control over the things that she could and managed to garden almost every day. She saw cancer as an

opportunity to cut toxic people out her life that she might not have otherwise. Ultimately, Nancy felt grateful that she had gotten ovarian cancer because of all of the lessons she learned and new people she had met.

Nancy portrayed herself with so much self-confidence throughout the interview and was very clear that she was not going to let cancer get her down. She stated that her life mantra is “It is what it is. Deal with it.” Given this, I was surprised when she told me that she had not realized how strong she was until she had cancer. “I learned that I’m one strong cookie.”

The same week that I met Nancy, I interviewed Kenneth in his home. Kenneth was slowly retiring from his longstanding satellite television business after being diagnosed with prostate cancer about two years prior. When I talked with him, Kenneth was in his mid-sixties, had three adult children, and was in a committed relationship with his girlfriend. We sat outside on his patio overlooking a beautiful backyard and talked for almost two hours.

For years Kenneth was expecting that he would eventually be diagnosed with prostate cancer. His uncle and father passed away from prostate cancer, so he had been vigilantly getting checked twice a year for the past 12 years. He stated, “I’ve been kind of expecting an onset at some point.” When he had a suspicious PSA test and subsequent biopsies, he was not surprised when he was diagnosed. “Well, it wasn’t unexpected. I felt I was not shocked either. It just turned me on to I’d better get more knowledge of—about what the next phase is going to be. And concerned for my role in the family and job and stuff like that mostly. I’m not life preservation at any cost. I’d rather not be here than have a long extended bout with cancer.” After receiving his diagnosis, Kenneth met with numerous doctors to discuss his options and to find the best course of treatment. “It’s a long road from the recognition of the presence of the cancer to what you’re going to do about it.”

Kenneth had multiple options and was able to spend almost 9 months deciding what he thought would be the best treatment to preserve function and remove the cancer. Ultimately, Kenneth decided to move forward with surgery and have his prostate removed. He opted for the robotic prostatectomy and was able to walk out of the hospital 24 hours later. After taking the weekend off of work, he was back to work by Monday. Looking back, Kenneth realizes that he needed more time off work, because while he did not have physical limitations, he still was not fully prepared.

You know even with the preparation I wasn't really prepared... What I wasn't prepared for was kind of a—my body wasn't prepared to do what I thought I could do. I guess because of the lack of intrusiveness of the surgery, I wasn't debilitated, but I had a lot of physical and mental adjustments to go through... It does impact you in a number of ways mentally.

Kenneth took months to meet with numerous doctors and decide on the best course of treatment but still talked about feeling out of control throughout the experience. He compared this feeling to being trapped in a wave. He stated that the most difficult part of his experience was the unknown:

A big body of unknown, it's a little bit like thrusting yourself into a new universe... You can get really lost in it, you can tumble like you do in a wave out on the—when you're body surfing. You can get killed, and the undertow is scary, you know going out here is a little less because the slope is so gradual, but there are times where I felt like I was in a wave at Rehoboth,³¹ and I just really being chewed up.

When I asked if he still felt like this or if this feeling of the unknown was tied specifically to his diagnosis, he responded:

It's continuing, it really just comes when you're more vulnerable mentally. And it shifts from just the physical aspect of it to now more of the mental aspect, but it's less turbulent, it's more subtle. So it's more nuanced than you know—the initial turbulence was violent and “oh my God, and am I going to die,” and you know a

³¹ Rehoboth is a coastal city in Delaware that Kenneth had referenced going to as a child. I also vacationed at Rehoboth as a child and we had a shared knowledge about the severe undertow and harsh waves there.

lot of uncontrolled fears. Now it's you know, "what's the new normal? What can I next expect?"

Even though Nancy had no time to decide on a course of action and faced years of rigorous treatment, Nancy described feeling confident that she was going to beat her cancer. She focused on what she could control. Kenneth, however, described feeling very vulnerable. When I asked Nancy how her sense of self had changed since her diagnosis, she stated, "I'm probably more confident." In contrast, Kenneth said, "There's a whole lot of vulnerability, all that mortality, all that—the loss of control and vulnerability." Additionally, while Nancy spoke about how grateful she was for the changes that resulted from her experience, Kenneth was surprised that others might have described their experience in that way.

Kenneth and Nancy had been diagnosed at about the same age, were both currently in remission, and had had their internal reproductive organs removed (the ovaries and the prostate). However, their stories diverge when discussing how they perceived their "self" throughout their cancer experience. Kenneth expressed anxiety and loss of control. Nancy, on the other hand, recognized her strength and found her confidence. Nancy's story is very similar to the stories of the other women I interviewed. Women talked at length about how their cancer experience allowed them to recognize how strong they really were. Additionally, Kenneth's story is also similar to the other stories of men in my study who, for the first time, confronted weakness and mortality. In this chapter, I will show how cancer allows women to feel empowered, while it challenges men's power and masculinity, leading to them feel out of control.

Before I start discussing the ways that women talk about empowerment and strength and men relay concerns about vulnerability, I will quickly review some relevant literature.³²

Masculinity and femininity are relationally defined. Masculinity is composed of qualities that are

³² For a more detailed explanation of the gender theory that illuminates my study please refer back to the introduction.

defined in opposition to femininity. While masculinity is defined by aggressiveness, power, rationality, leadership, ambition, assertiveness, competitiveness, independence, individualism, and self-sufficiency, women are expected to be passive, weak, emotional, illogical, affectionate, compassionate, gentle, gullible, shy, sympathetic, tender, and warm (Connell 1987; Ridgeway and Correll 2004; Schippers 2007).

Because traits like being gentle and compassionate are associated with women, men learn that they should avoid these traits in order to preserve their masculinity. Men who fail to be strong and self-reliant are punished; similarly, women who fail to express warmth and compassion are chastised (Cuddy et al. 2008; Prentice and Carranza 2002). From a young age, men and women learn what is expected of them and these gender stereotypes become embedded in their understandings of their own self-identity. As men grow up learning to be strong, independent, and assertive, women learn to emphasize their warmth and vulnerability. As a consequence, women are routinely told that they are the weaker sex: physically and emotionally. Consequently, men learn to demonstrate hegemonic masculinity by emphasizing their authority, denying vulnerability, and avoiding behaviors that they associate with women (Connell 1995; Courtenay 2000; Hollander 2001).

Cancer provides women with the opportunity to recognize that they are strong, contradicting their prior belief in their weakness. Men, however, have learned to maintain authority throughout their lives and have always been expected to be strong. Therefore, cancer challenges men's control and subsequently their masculine identities. Below, I show how cancer allows women to recognize their strength—physically, mentally and emotionally, and through self-advocacy. In the subsequent section, I outline the ways that men feel disempowered due to their experiences with cancer.

WOMEN REALIZE THEIR STRENGTH

Nancy recognized her strength by becoming her own advocate, and she joked that she is now “one tough cookie.” Just like Nancy, 85% of the women in my study recognized their strength, even though these women were at different stages of their recovery. I interviewed women with recurrent cancer who were undergoing treatment, women who had recently finished treatment, and women who had been in remission for years, and all but five of them mentioned strength as the primary thing they learned from having cancer. For example, when I asked Tammy, a 51-year-old breast cancer survivor, what she learned about herself, she succinctly stated, “That I’m strong.” Rebecca, a 44-year-old ovarian cancer survivor, noted, “I’m strong. I can laugh. I’m a good person and it wasn’t my time. That I know. Those are the main things.” Patricia, a 73-year old ovarian cancer survivor responded, “Well I guess I learned I’m stronger than I thought and my children see me as strong and I’m happy about that. That makes me happy.” When asked to reflect upon the lessons they learned about themselves, like the other women interviewed, Tammy, Rebecca, and Patricia immediately said that their experience with cancer revealed their strength.

Women were consistent that the key thing they had *learned* about themselves was that they were stronger than they had originally known. The assumption that women are inherently weak was so engrained in the female respondents that they were surprised to realize they were capable of being strong. The very fact that these women emphasized that they *learned* that they were strong shows how they did not recognize this characteristic within themselves before.

While discussing their experiences, these women drew on three narratives of strength: 1) physical strength, 2) mental and emotional strength (especially courage and bravery), and 3) strength through power (or advocacy). A cancer diagnosis and the subsequent treatment

challenges individuals' mental/emotional and physical strength. The realization that their minds and bodies can withstand this trauma is empowering for women.

Physical Strength

Enduring the difficult treatment helped women realize their physical strength. Fifty-two-year-old breast cancer survivor Kimberly realized that she was more physically strong than she previously assumed, because she continued to hike with her husband while going through chemotherapy. Kimberly stated,

I have come to realize that I am a very strong person. I'm sorry (*starts crying*). I am also stubborn when I want to be. And—but yeah, I would say that one of the biggest things I realize about myself is that I am strong, and you know you—when I—when we take our hikes now, and we're climbing out those mountains, I think to myself, how in the world did I do this when I just had chemo a week ago, you know or I just went through radiation or surgery. So yeah, definitely very strong.

Her physical strength to continue hiking, even during her chemotherapy, helped her get through her experience without letting the chemotherapy take over her life. Strength was often implicitly connected to being physically strong enough to endure treatment. Linda, a 74-year-old breast cancer survivor, responded, “And I guess I learned that I could—I could meet it, and get through it, and I was ready to do what—to give it a go, no matter what—what it was going to be. And I guess I learned that, you just go for it.” Linda learned that she could get through the surgery, chemotherapy, and radiation by facing it head on. While this was physically very challenging, it helped Linda recognize that she was strong and could handle more physical suffering than she knew.

Mental and Emotional Strength

Culturally, being strong is often connected to physical strength. However, women emphasized strength as more than just being physical. For many women, learning that they were

strong was a realization of their mental strength. Being strong for women was not about being unemotional—some women even cried when talking about their own strength. Being emotionally and mentally strong was about being brave and resilient while not letting negative emotions get the best of them.

Women recognized that their strength was not compromised by their emotions. Being emotional was acceptable as long as their emotions did not dictate their lives. This is exemplified by Judy, a 69-year-old woman with breast cancer, “I think I feel like I’m stronger than I thought. I thought I would fall apart honestly. I thought I would just be a little depressed kitten running around.” Judy distanced herself from being depressed when acknowledging her strength. Judy expected that she would be unable to handle the diagnosis and the treatment, especially because she was someone who was rarely sick and very opposed to medical intervention. She noted that she does not even take Tylenol when she has a headache. But with the support of her son and her friends, Judy managed to get through her treatment emotionally and physically without falling apart.

Gloria, an 81-year-old ovarian cancer survivor, also expressed learning about her emotional and mental strength. Gloria was diagnosed with and treated for cervical cancer when she was 45 years old, but her ovaries were not removed at the time. She was then diagnosed with ovarian cancer at the age of 79 and had a full hysterectomy. After being in remission for a year, she was told that her ovarian cancer was recurrent. At the time of our interview, Gloria was going through her second round of treatment. Even though Gloria was currently going through chemotherapy, when I asked her what she learned about herself, she said:

That I’m tough, and I’m a survivor. And that I’m an optimist. And you know I really feel I can overcome most things, you know, I’ve had to. I’ve had, you know, I nursed my husband for five years with cancer and my sister and all of that. And yeah, I think that the more battles, well battles maybe is not the right

word, but stringent circumstances you have to—they either do you in, or they make you strong. And I like to think that it's made me strong you know, and a weeping mess, you know. I don't cry very much, and I mean I cry at sad movies, and so forth, but I don't cry for myself very much at all. I don't see any reason to.

For Gloria, crying at a sad movie does not take away from the fact that she is tough. She is able to be emotional and let out her feelings without letting those emotions take over. She laughed about being a weeping mess because a few times during the interview she would get teary-eyed talking about her children and grandchild. However, Gloria was indeed not a weeping mess despite occasionally getting choked up during our interview. Gloria was clear that she would not let sadness dominate her life. Gloria overcame numerous obstacles, including the loss of her husband, but she did not feel bad for herself. She did not focus on the negative things in her life, and she refused to give up.

Oh, I just feel so blessed, really, that I've lived this long and that I can survive all these things that happened to me, you know. And I really think I'm going to live longer you know, I really expect that, you know. If it doesn't happen, it doesn't happen, but you know, I'm planning on it, and still making plans, so yeah, life—you don't want to waste it. And cancer gives that to people, you don't want to waste a day, you know if you're going to do something do it. If you need to say something to somebody, you'd better be about saying it, and so I think the urgency that you have to do the things don't put off doing things, you know.

Gloria was going through her third round of cancer treatment in her lifetime and continued to emphasize that she was strong and blessed because of her experiences. Her mental and emotional strength got her over obstacles and through her continuing cancer treatment.

Laura was diagnosed with ovarian cancer 18 years prior to our interview at the age of 38 and had residual complications for much of the last 10 years. When I asked her what she learned from her experience with cancer, she stated:

That I'm a lot stronger than I thought I was and what else? I guess that's it. I think stronger mentally, you know, and I think everything else just falls into place 'cause if you're not strong mentally then I think that you could really give in to the illness and just let it be more than what it should be, you know. I think your

attitude plays a big part in it. I mean I know that I've been severely depressed through the process of it but I think I was depressed before, you know, and just never knew it.

Laura recognized that her mental strength was not compromised by her depression. She was able to be mentally strong throughout her experience, which helped her fight her cancer without letting depression take over. Women repeatedly mentioned not “giving in to the illness” and refusing to “fall apart.” Continuing to get treatment and fighting through that treatment without letting their depression, anxiety, or emotions take over were ways that women recognized and referenced their strength. These women contrast their understandings of themselves against people who have a “woe is me” attitude and give up.

Additionally, Janet, a 55-year-old gynecological cancer survivor, recognized how strong she is while allowing herself to be more emotional, “Well I see myself as strong... I think I see myself as softer now, more willing to be more emotional, more willing to talk about how I'm feeling or my fears or my beliefs with people that I may not have revealed.” Janet's newfound openness to being emotional does not go against her belief that she is strong. Across the women I interviewed, mental strength does not mean the absence of emotion.

As I have previously mentioned, women consistently discussed how *surprised* they were that they were mentally strong enough to handle this experience. Jennifer, a 44-year old ovarian cancer survivor stated,

I'm a lot stronger than I thought I was, you know I heard a lot about—I heard a lot of people define—or describe me as being very courageous and brave and that I went through this kind of in style, or which are not things that I guess I really thought about myself in that way. But yeah, I mean when I would talk to the nurses, you know you've got a very positive attitude about things, and that will help you going through the chemotherapy experience. So yeah, I didn't realize that I could be that strong or brave about going through that treatment.

Jennifer equates being strong with being brave and because she never saw herself as brave or courageous before she was surprised to realize that she possessed those traits. Like Jennifer, most of the women I interviewed did not identify themselves as mentally and emotionally strong most of their lives and were surprised at how brave they really were. Courage and bravery was also understood as confidence. For Shirley, a 66-year-old gynecological cancer survivor, cancer helped her recognize her strength and ability.

Oh, it has established for me an identity that I only dreamed of. I am confident; I am capable... I just am proud of who I am really proud. And I don't think that I would be able to say those words as confidently, probably confidence is the word that sums it up. Ten years ago that would never cross my lips, would never have crossed my lips, that's who I am today.

Shirley would never have described herself as confident prior to her diagnosis. She now sees herself as someone who is capable of facing adversity and is proud of that strength. Sentiments about being stronger than they ever thought or ever expected popped up, even as women defined strength in different ways.

Advocacy as Strength: "I did it for myself."

In addition to mental fortitude and physical strength, women also felt stronger because they learned to advocate for themselves and put themselves first. When asked what she learned about herself, 42-year-old breast cancer survivor Felicia stated:

That I am strong; that I am resilient... You have to be your best advocate to find out what's going on and make sure you have the right people on your team. Even if that means doing something that you that might be a little outside of your norm; try to take my own advice in that way.

For Felicia, it was unusual put herself first, especially as the mother of two young boys, but her experience taught her how to be her own best advocate. Navigating the medical field successfully helped her recognize her strength and resilience.

Margaret, a 60-year-old breast cancer survivor who is a singer, pushed for additional tests

that indicated that chemotherapy would not have done much good. She refused radiation in order to spare damage to her lungs. When I asked her what she learned about herself she stated,

I'm much stronger than I expected. I can't believe it, but I saved myself from chemotherapy and radiation by doing work, the work that no one else was going to take the time to do, I did it for myself. So I'm *amazed*. *I'm much stronger than I thought. It still amazes me that I was able to do all that research.* (emphasis added)

Margaret amazed herself because she was able to collect information and make decisions on her own. Her strength is defined by her self-advocacy. Doing research on how to manage her treatment helped her decide against chemotherapy and radiation. "So I went into all the medical journals and brought whatever statistics I could find to my doctor and we determined that we would just try the Femara and so I didn't need radiation or chemo." Her self-advocacy was significant in deciding on her course of treatment with her doctors, and she was still amazed that she was able to do it. This self-advocacy helped Margaret develop a stronger sense of herself, which rolled into her life more broadly, allowing her to put herself first.

I have much more of a sense of self than I ever had. I never thought about myself. Now I think about myself. And I think about—yeah, I think about myself, like sometimes I don't want to do something that I might feel obligated to do or have felt in the past obligated to do. And now if I don't want to do it I say no, I don't think so. So I think about how things are more than I ever did about how they're going to benefit me personally, which I never did before. You know we're kind of taught not to think about ourselves, now don't be selfish, you shouldn't be selfish. But I don't worry about that anymore because I do think about myself. It sounds weird. Because it goes against the way I was raised, you know. You do for others and you don't think about yourself and everything is this and this and this, and if you—don't do things for yourself because others or—you might perceive it as being selfish. So I don't think about that and I gave that up.

Margaret's experience allowed her to learn to put herself first when she had spent the last 55 years focused on doing things for others. When I asked her where she thought her selflessness came from, she responded, "Absolutely because I was a mother because you want to do for your children, you want to make them happy. I elected to be a stay at home mom. I wanted to be home

with my kids.” As a woman, and as a mother, Margaret felt like she had to put everyone else first. Her cancer experience and her ability to advocate for herself taught her that she was not being selfish by thinking about herself.

Like Margaret, Janet, a 55-year-old, ovarian cancer survivor, also stated that she has learned that she is strong, “Well that I am stronger than I thought.” However, unlike Margaret, Janet has recurrent ovarian cancer that she is still being treated for. During the interview, Janet acknowledged that she was preparing for her death. Even though she sees herself as “walking hand-in-hand” with her death sentence, Janet still feels strength and empowerment. And when I asked her how she felt strength, she said, “So what’s changed in me is that I don’t have to be so independent. I can lean on other people and be comfortable in doing that. It’s okay to ask for help and it’s okay to ask for people to pay attention to you and you’re not being selfish, and sometimes it can be all about you, you know.” For Janet, feeling stronger meant learning to prioritize herself by asking for help and comfort. As a mother, who had been a major source of support for her son, Janet learned that she is also in need of support, and she is no longer afraid to ask for it. Prioritizing herself and asking for others’ attention has allowed her to recognize her own strength and was helping her get through her experience.

Similarly, Tammy, a 51-year-old breast cancer survivor, stated, “I think it made me stronger.” When I asked her to describe what that meant, she followed up, “I’m not as afraid to tell people, like my boss, to tell her if what she wants is unreasonable, of course, in a nice way. I’m not afraid to stand up.” Tammy’s strength comes from her ability to stand up for herself, something that she felt uncomfortable with before having cancer. Pamela, a young mother, who was diagnosed at the age of 42 with rectal cancer, states:

I used to be a pleaser, a giver. I still am but a smaller scale. I have to, before I say yes to everything I have to really mentally stop and think about do I have enough

time for this and what's going to lack if I do commit myself to this or the other thing. I don't know just kind of, I just go at a slower pace and a lot less stuff on the agenda.

After her diagnosis and treatment, Pamela made the decision to prioritize herself more than she had before. While she always wanted to please others, she has taken that down a notch.

Self-advocacy also meant doing more for oneself and less for others. Barbara, a 74-year-old ovarian cancer survivor, learned she could put herself first and did not need to repress how she felt. Barbara has a very restrictive diet after complications from her surgery created blockages in her bowel (leading to additional surgeries and related treatments). She had been in a toxic relationship for years until her cancer diagnosis. Her ability to deal with these complications and ending her long-time relationship helped her realize that she is tougher than she thought she was.

I learned that I was stronger than I thought I was, and that you know you can—it's amazing how you can live with so many restrictions and I mean I'm thinking my diet, and the situation I'm in. I've learned that I'm pretty tough that way and that when I'm honest, I'm better off and happy. And when I say honest, I've never been a dishonest person, but I mean the dishonesty of repressing, so repressing feelings and reactions and that sort of thing. Instead of—I always wanted people to like me and I know the right answers and I know how to do that. And that's how I was able to stay in that relationship for so long. But I don't do that anymore.

And when I pushed Barbara on whether she thought these feelings were a consequence of her cancer experience she continued, “Yeah, I do. And one of the ways that I'm different is not responding to other peoples' needs like I used to—I'm more selfish, but in a good way.”

Barbara's her realization that she does not have to please others and repress her own feelings is an example of the ways that cancer helped women learn to value themselves and their own desires and wellbeing. Being honest with her feelings and reactions has allowed her to find more happiness and end toxic relationships.

Asking for help and putting themselves first is seen as strange for women because they are accustomed to taking care of others, especially as 26 of the 32 women I interviewed were mothers. For example, Rebecca, a 55-year-old ovarian cancer patient, spent a great deal of our interview talking about her support system, which included her immediate family, members of her church, and other friends. While she was grateful for the support, she mentioned how difficult it was to learn to ask for help.

When I'll just make a generalization. And I can't say it's *just* because I'm a woman. I feel that I've normally been the one doing the giving and the caring and you probably hear this with the other patients. When you need to ask for help for yourself it's more difficult. And then to receive it gratefully and not feel like you owe them so much, you know. That was something I had to learn is accept it, take it in. (emphasis added)

As part of her feminine identity, Rebecca was accustomed to prioritizing others. However, she realized how much she needed other people to get through her chemotherapy. While asking for attention was difficult, Rebecca realized how valuable it was to get comfortable asking others to put her first. Becoming an advocate and asking for help allowed women to see themselves as strong. For women who have always put others first, letting others help you and making you a priority becomes a sign of strength rather than weakness. Caring for and prioritizing the needs of others is a symbol of femininity, and while these women had embraced these feminine ideals their whole life, they recognized their strength in moving past these cultural conceptions.

In addition to being more assertive about their own needs, women found numerous ways to become their own advocates and take control over their situations and treatments. Like Margaret who enjoyed doing all of the research on her own, Denise, a gynecological cancer survivor, stated, "So when I had spoken to my acupuncturist I used in the past, she said, 'Okay. Get on a low inflammation diet, start drinking dandelion tea,' you know a bunch of stuff. So I followed it, *and that made me feel more in control too. Like I could do this*" (emphasis added).

Making changes to her diet helped Denise feel in control and gain the strength to face her treatment. Even though many of the decisions for her treatment were pre-set, Denise decided to do what she could on her own, which allowed her to feel like she had control over the situation. Cynthia, 48, a breast cancer survivor, described a similar story when discussing how her nutrition class allowed her to gain knowledge and power.

I didn't want to eat and then, you know having a doctor who was saying it doesn't matter what you eat, but reading so much about that it did matter. So that was the first thing I went to was the nutrition class. And you know again, it was somewhere to go to fortify my knowledge and my resolve, and what the things that I did have control over that could impact my health. *And that was important to me that I had some power because you need to—you need to feel like you have some power in this thing that just fell into your life. So that's what it did, it empowered me, and it did it like big—huge—it made a huge difference.* (emphasis added)

Having even the slightest bit of control over her experience gave Cynthia a sense of power.

Gaining nutritional knowledge thus helped Cynthia recognize that she was stronger than she thought.

Additionally Judy, the 69-year-old woman with breast cancer who earlier mentioned that she expected to fall apart, discussed how collecting information and doing research made her feel stronger.

I think that I'm stronger than I thought probably. I've never been tested really much so I didn't know what I'd do when things really struck but, you know, it wasn't a big bad thing. I mean there's certainly worse things people go through, but it's definitely threatening to your psyche; just the idea of having the big C; and then having part of your body removed and going to the hospital and going to all this stuff. I think in a way I honestly enjoyed some of the stimulation. I mean it was so interesting to delve into all this and just see what's going on and get kind of involved in something that much. I think that's why I enjoyed making my notebook so much, I just love having all the information. It's kind of like a project, it's like a college project or something, it's just interesting all the stuff you find out. I think I came through it better than I thought I would.

Judy's strength was reinforced by her ability to do so much research and navigate the medical field. Judy was very proud of the notebook that she had made and kept it with her throughout the interview. Her notebook allowed her to feel a sense of control. She was able to collect information and organize the materials in a way that made sense to her and made her feel good about herself. This type of self-advocacy allowed her to recognize the strength that she had within her that she had not known prior. Women used nutrition classes, research, and changes to their diet to advocate for themselves. This advocacy helped them recognize their strength and feel empowered.

MEN FEEL DISEMPOWERED

At the beginning of this chapter, we saw that Nancy learned that she was “one tough cookie.” Kenneth expressed a very different sentiment, “There's a whole lot of vulnerability, all that mortality, all that—the loss of control and vulnerability.” Kenneth felt like his cancer experience was analogous to getting caught in a wave—feeling out of control and facing his mortality. While women consistently recognized strength as one of the primary things that they had learned about themselves, men were not nearly as consistent. Men gave a wide variety of responses. Rather than talking about strength, most men stated that they had not learned anything new about themselves or, like Kenneth, were forced to confront their mortality. As men are expected to maintain control within their families and at work, their strength and power become taken-for-granted. Hegemonic ideals lead men to deny their vulnerability, and as a consequence, when they are confronted with a cancer diagnosis, men's conceptions of their masculinity and self-identity are challenged. Cultural expectations for men to maintain strength become challenged.

Because there is the taken-for-granted assumption that they are already strong, many men told me that cancer taught them nothing about themselves. Edward, a 66-year-old prostate cancer survivor said,

I don't think I really learned anything new. I've always been able to deal with adversity and difficult decisions pretty carefully and without a lot of emotion and drama. Just kind of, you know, do your research, suck it up, be stoical, a lot of people have it worse than you. Maybe it's more confirmed or affirmed how I deal with adversity. I don't think it's changed—there's been no new major revelations.

Frank, a 65-year-old prostate cancer survivor, admitted, "I don't know; I don't know that I've learned anything about myself because, and you touched on this question earlier, is that this is just the way I am. So I haven't surprised myself because this is just this all seems normal to me." More succinctly, Gary, a 70-year old prostate cancer survivor, just responded, "Nothing."

These men stated that their cancer diagnosis and treatment did not change their views of themselves at all. This is in stark contrast to the women who were surprised to realize their strength. Some men, like Edward, already felt capable of facing adversity. For their whole lives, many men internalize the idea that they are naturally strong. Therefore, for the men who continued to feel strong throughout their experiences with cancer, the disease did not challenge their perceptions of themselves in the same way that it did for women.

Other men stated that being diagnosed with cancer forced them to grapple with their mortality. For example, Eric, a 42-year-old testicular cancer survivor, responded,

I think it made vulnerability more concrete at the time. You know, I would have been in my late 30s at the time. I had health problems when I was too young to know but prior to that and since then I really didn't have any sense of mortality or vulnerability other than in my professional experience. So it made it much more personal to know that life is temporary and that having gone through that I think it's made me, like, and it sounds cliché but certainly appreciate the day-by-day, the small things that happen.

Eric had been sick as a young child but since then had never questioned his mortality. A testicular cancer diagnosis challenged Eric's taken-for-granted ideals. Just as Eric's strength was challenged in his late 30s, so was William's. William was diagnosed just a year earlier with testicular cancer. When I asked him what he learned about himself, he responded:

So at 35, I learned that life is vulnerable. Any, I guess, life is vulnerable, just think young people who are younger, when I was younger, you know, you shouldn't have to worry about your mortality and all this stuff but it's a very real thing that life is precious and life can take you away at any point and realizing that was a really shitty thing, and you know you hope nobody else goes through that, but it's just taught me to, I guess, appreciate things now more than I did before.

Similarly, Matthew, a 33-year-old testicular cancer survivor, stated, "I'm not invincible."

But it was not just the young men who learned that they were mortal. Terry, a 63-year-old prostate cancer survivor said, "It makes you see that you could be vulnerable, that you're not invincible." Men are assumed to be strong throughout their lives. As a consequence, their masculine identity becomes wrapped up in denying vulnerability. Cancer challenges these masculine ideals by forcing men to come to terms with their mortality.

While women feel empowered and stronger, the opposite effect occurs with some prostate cancer and testicular cancer survivors. Instead of feeling stronger, many men face feelings of weakness. For example, Jeffrey, a 43-year-old testicular cancer survivor, stated,

In some ways I'm not as strong as I thought I was. This first oncologist we went to, and I never really thought that I'd die—I thought I might have a hard fight but I never thought I would die, and that doctor sat me down and said—he just said we're going to get you through this. And for some reason that just made me start crying like a baby and I'm a guy that never cries at funerals and stuff like that. So in some ways I found out I wasn't as macho as I thought I was I guess.

Jeffrey did not feel empowered. For Jeffrey, hearing his diagnosis forced him to realize that he was not as strong or as masculine as he thought he was. Jeffrey's quote is a clear example of how strength and masculinity (*i.e.*, machismo) are connected and conflated. Further, in opposition to

women, Jeffrey saw being emotional as a sign of weakness. For Jeffrey, “Crying like a baby” illustrated that he was not as masculine as he had always thought.

Similarly, William, a 36-year-old testicular cancer survivor, distanced himself from the strength narrative that he heard from health professionals and friends:

So there’s this thing that people always say to people who survive cancer. They say like they’re so strong and I don’t know if I agree with that. I was a guy who got sick and I got medicine and I got better. When you break it down to its simplest form that’s all that really happened. I got sick, they gave me medicine and I got better. So I’m not really strong because of this. It made my body strong because it survived this but it didn’t survive it willingly. So I don’t know. Like that’s just kind of how I feel about it.

For William, getting through his diagnosis and treatment did not make him feel any stronger. He essentially did what he needed to do, and that was that. Other men made similar arguments and actively distanced themselves from the strength narrative. Men routinely argued that it was not their own strength that helped them survive. For Nicholas, a 23-year-old testicular cancer survivor, it was luck. He stated that he did not overcome his cancer experience by being strong or having an extraordinary amount of willpower.

Like I felt like I didn’t fight it, like I just let the doctors treat it. You know I didn’t have like any extraordinary amount of willpower, whatever, and people say, you know, you’re a strong person for going through that and I don’t really think—I mean I think that anybody who had this happen would have to develop some kind of sense of being able to get through it. I think everybody would and it would change anybody. So that I don’t think it’s some, you know, amazing thing about me that I survived. It’s that I’m lucky.

Additionally, Thomas, a 75-year-old prostate cancer survivor, stated that he learned, “That I’m human and vulnerable to all the sicknesses and life, you know. I met a lot of guys with this diagnosis and some guys were extremely unlucky and I consider myself very lucky.” In addition to realizing his vulnerability, Thomas stated that he has survived cancer out of complete luck and not due to any strength of his own. Thomas also recognized that perhaps he is not as strong as he

had originally thought. He realized that he is human and vulnerable. It is significant to note that men of all ages chalk it up to luck. Both Nick (23 years old) and Thomas (75 years old) believe that they were just lucky.

Men distanced themselves from arguments about strength and focused on luck or the importance of good doctors, while women routinely noted that it was their own strength that got them through their experience. As opposed to feeling empowered, men noted that they learned more about their weakness. Most men discussed feeling mortal and vulnerable, said they had learned nothing new, or argued they did not overcome cancer due to their own personal strength. I argue that men's gendered identities are not strengthened, but rather fractured, as the cancer diagnosis strips them of the power previously bestowed on them as white middle-class older men.

Men Lose Control

When asked about the hardest part of their cancer experience, most men discussed their trouble with the uncertainty and lack of control. John, an 81-year-old prostate cancer patient, stated that the most difficult part was “Making the decision [around treatment], the emotional decision.” Similarly, Jerry, a 66-year-old prostate cancer survivor, stated that the hardest part of his experience was “Finding out about it. You know realizing that I wasn't invincible. Because I had never had any surgery before that, I never had a broken bone, so I'm saying having a doctor tell you, you have a cancer is a shock to the system.” Jerry notes that coming to terms with his mortality was hard, but so was just finding out about the diagnosis.

Uncertainty came up time and time again as the most difficult part of the experience for men. Edward, a 66-year-old prostate cancer survivor stated,

It's dealing with the—kind of the uncertainty or the lack of clear-cut treatment options. Or, the timing of it. It's not—you know, it's not like when you call up

and you have chest pains, get him into the emergency room and he's got three clogged arteries, it's nothing like that. There's time. There's time to be had. It could be double edged. And, I'm—you know, I don't like to leave things to chance.

Edward felt great anxiety in between tests and learning results because there was so much time.

His biggest struggle with the cancer experience was the uncertainty about what to do, which treatment to have, and what the lab results might show. These outcomes were out of his control, and the uncertainty created a great deal of anxiety.

The lack of control also greatly affected Thomas. When asked about the most difficult part of his experience, he answered:

Waiting for the treatments to start, waiting for the treatments to end and not knowing what was going on. I worried about outcomes, consequences. I'm much more relaxed about it now but if it returns I wonder—well I'm not gonna panic or be spooked the way it—I was before, but I know I'll definitely you know—I'll probably feel—have return of these old feelings of dread. A sense of dread, like well the end is in sight now, isn't it? That sort of thing. It's something hanging over your head, something about to fall on you.

This uncertainty and lack of control created a sense of dread. Not knowing the right treatment choice was a huge concern for prostate cancer patients because they were often given multiple options. Generally, prostate cancer patients are given the choice between surgery or radiation, and they have more time to make their decision because prostate cancer is less aggressive. The uncertainty about whether they were making the right choice caused many prostate cancer patients to feel like they lacked control in their treatment. This is paradoxical given that men with prostate cancer literally have more control over their treatment.

In contrast, testicular cancer patients almost always have surgery, and surgery is generally scheduled right away. Importantly, testicular cancer patients still noted feeling out of control. Joshua, a 29-year-old testicular cancer survivor, stated,

I'm a control freak and I'm putting my life in the hands of a stranger. I want to, you know, make sure that that person, especially—I mean I'm not going to like—I don't like screen the pilots on planes or something like that, but at that point I have no other choice, but with my doctor I wanted to at least have that sense of control. I had no control over the cancer and it happened all so quickly that if I can control anything it would be my providers.

Joshua tried to regain some power by researching his oncologist and ensuring that his oncologist was the best one to treat him. This task felt like the only part of the process that Joshua had any say over. This lack of control created anxiety for him and many other men because for the first time in many of their lives they lost the power and authority that had been bestowed to them as men. Cancer took command over their bodies, and they felt uncertain about their options, their doctors, and the future.

When I asked William, a 36-year-old testicular cancer survivor, about most difficult part of his experience, he answered,

It was and continues to be the mindfuck of it all, just the thing that you never want to think about that you think about, right, like “hey if I die, do I have my family set up okay to be financially sound and stable?” And like “what are my friends going to do, what's my family going to do, what's my mom going to do?” Like you know, all those weird things.

His cancer diagnosis created a lot of uncertainty for William. He was concerned about taking care of his family and making sure that they were financially secure without his income. Being the provider of the family for men is tied to the same type of control that is implicit and idealized in hegemonic masculinity. Men's concerns that they can no longer provide for their families challenge their authority as men.

This “mindfuck” of the uncertainty caused by having cancer was reiterated time and time again by other men. Eric, a 42-year-old testicular cancer survivor, said of the most difficult part of his experience:

For me no doubt it was the first, the most difficult [part] was telling my parents that first day. Then secondly, the time of the waiting to find out what the tumor type was, to planning treatment, and having no experience to know what the next six months or a year would be like, and how often scans would be. So prognostic uncertainty I guess was the second most difficult part. That was mostly wrapped up once we got the path report and had a plan. But beyond I think the hardest part was the first few days telling people that didn't know and sort of opening up about it.

The waiting and the uncertainty made men, like Eric, feel a loss of control. Similarly, James, a 28-year-old testicular cancer survivor, said,

I guess the most difficult part would be, probably, just not knowing, you know, from appointment to appointment what's going to happen. Whether this is all going to like smoothly, and it's going to be forgotten and not forgotten in ten years but kind of an afterthought or whether I'm going to end up you know I know at the end of the day I could die from it. That's the part that I don't, it looks difficult, as not knowing that it could go from each extreme.

For James, both the unknown between appointments and realizing that he was mortal proved challenging. Similarly, Jeffrey, a 43-year-old testicular cancer survivor, explained,

Just facing it. I guess cancer is such a scary word. And just the uncertainty the whole time because cancer is such a waiting game. You know they're, "okay, we're going to do this and then we're going to test you and we won't know the results until then but we still don't know, it still might come back." And like even now four years out I just had a CAT scan like I said last Friday and I go to oncology Tuesday. You're still just this constant waiting and you never really feel like you're done with cancer, you never really feel cured.

Cancer diagnoses created a lot of ambiguity for men, particularly as they were forced to rely on other people schedules, wait for test results, and continued to get screened and checked for reoccurrence. This lack of control is in opposition to the amount of control that they had grown accustomed to as predominantly middle-class white men. Having to confront this lack of power altered men's perceptions of their identities in drastically different ways than it had for women.

Cancer challenged men's assumptions about strength and control and because masculinity is so intertwined with these cultural expectations.

Men Become Emotional, Empathetic, Considerate

Men's masculinity was challenged as they faced their mortality and managed a loss of control in their lives. As a consequence, men noted that their cancer experience had made them more vulnerable emotionally. Roger, at 72 years old, said, "I mean more vulnerable than I thought I was. It brings a little bit of reality, wake-up calls, things like that." His wife jumped in and added that he was more sensitive now than before and he agreed. In addition to being sensitive, men discussed feeling more empathetic and understanding of other people, prioritizing other people, and becoming more social. For example, when I asked Kevin, a 39-year-old testicular cancer patient, what he thought was different about himself since his diagnosis, he said,

I tend to care for other people first, you know, instead of going, you know, take care of yourself and then worry about other people. Generally throughout the whole experience I had people, you know, that would tell me "hey, man, why are you worried about me? you know, you got to deal with this." I don't know, "it's just on my heart man." I got to, you know, make sure other people are okay. People seem more dear to me. Before all this, you know, I wouldn't give the time of day to them or anything like that, not that I didn't want to, you know, I thought quote unquote I was too busy to do anything like that.

But now I cannot give back enough to just give back because people gave to me, you know, so much... So giving back, me caring and giving back to other people is—that's how I've changed through this ordeal.

Kevin notes that he has become more considerate of other people. While he would not have given other people the time of day before his diagnosis, he now finds that he's more likely to take care of other people than think about himself. Kevin is clear that this is a shift as a consequence of his cancer diagnosis and even while he was sick he wanted to help take care of other people. Similarly, William, a 36-year-old cancer survivor, said that he was less of an

asshole, more considerate, and less selfish. When I asked him what was different about himself now, he said,

I think I can feel more vulnerable and I value the little things more than I did before. You know I take time to do things that previously I would have not thought was something that I wanted to do and I'll just do them now like apple picking with the baby, you know, and stuff like I'm like that doesn't sound—like I'd rather sit home to watch football than go apple picking, but now I'd rather go apple picking and it's because there are some moments that you can't get back and, you know, although I'm in remission right now it doesn't mean that that will be the end of it and I don't want to miss those moments.

For sure. I'm different, you know, more understanding and I'm more compassionate and I just don't have a sense of—I don't know, maybe self-entitlement that I thought that I had before. It's just I like to put people first now.

William notes that he's more likely to prioritize other people and do things that his family would want to do over the things that he might have done prior to his cancer experience. He connects this with being more compassionate and understanding of other people. This goes beyond just his family—William notes that his co-workers also notice a difference.

Yeah, I think other people see me differently and other people tell me that I'm different but again it leads back to the whole not being as brutal, I'm not as blunt. I'm not as much of an asshole as I was before. I try to take feelings and people's situations into consideration. And that's a very, very hard thing—to take over people's personal issues in perspective but I do, I have to because—just because of what I've been through. I've been able to accept and adapt to that a little bit more.

William feels like he is more compassionate as a consequence of his cancer experience. John, an 81-year-old prostate cancer survivor, mentioned the same change. When I asked John what was different about himself now, he said, 'Well more compassion, more understanding, more forgiving and a better understanding of people who will accept help and others won't. More calm about it.' Similarly, Jeff, 43, "And before cancer I would never just go up to a friend and say hey, I love you and thanks for being you."

Putting others first and being more understanding was articulated in a number of ways. Some men mention being more patient, being more empathetic, being more receptive. Like Kevin, William, and John, Christopher, a 43-year old testicular cancer survivor, said, “I think it would be that I’m I try to be more patient; I try to listen better, and I try to enjoy life more than just worrying so much. Not being under so much stress.” Likewise, Joshua, 29, said that his cancer experience increased his empathy.

When I asked Donald, 75, what he felt was different about himself, he said “I’m certainly a more social person than I was because this brings you into social conditions and I’m basically not a very social guy. So I think from that aspect that yeah, I’m more open to other people and definitely more open to other people’s opinions now than before.” Donald also mentioned that he was never inclined to give back to the community before this experience and now wants to help other people which is why he has become active in a prostate cancer support group. Ultimately, Donald, notes, “I think I learned that I’m a little more receptive than I thought. I’ve always been a pretty headstrong guy and once I form an opinion that was pretty much it. I think the thing that I’ve learned is I can now bring other things into that scope that are beneficial to me and then to others. That’s the biggest thing.”

Unlike women who argued that they were stronger and more likely to put themselves first now, men note that they are more considerate and prioritize other people for the first time. Cancer challenged men’s mortality and took away a sense of control that was engrained in their daily lives as middle-class men. As a consequence, men felt more vulnerable and compassionate. I argue that men’s newfound empathy and selflessness can ultimately undo gender norms as men move away from hegemonic ideals.

EXCEPTIONS: SOME TESTICULAR CANCER SURVIVORS

Some testicular cancer survivors proved to be important exceptions, as five of these respondents (a third of the men with testicular cancer interviewed) expressed similar sentiments to the female respondents about learning that they were strong. When asked what he had learned about himself, James, 28 years old, stated,

I'm more resilient than I thought I was. Like normally, I would think that I would be on the ground crying, and I wasn't. But I wasn't really—like a couple of nice things they ever said is that I'm really strong for reacting the way I did, but I don't think I'm strong I think that's just to me that's my normal reaction. I just take a logical look at it and say well; I didn't cause it, and I can't stop it, so I just that's the way I deal with it; I know that crying isn't going to make a difference. Not even getting upset really isn't going to make a huge difference in what's going on. If you had told me 10 years ago I was going to get cancer I think I would have thought that I would have freaked out and been upset, and everyone else should have been upset. But I was a lot less emotional than I thought I would ever be about it.

James assumed that he would have “been on the ground crying” or “freaked out and upset,” but he realized he was more resilient than he thought. He explained that he was able to handle his cancer diagnosis and treatment logically and unemotionally. Similarly, when I asked Christopher, 43 years old, what he learned about himself throughout this process, he stated, “Oh definitely, I've learned that I'm a lot stronger than I used to give myself credit for. I've learned that life is unpredictable but that you can control your life to an extent, and that you can make your life, that you can change your life.” While Christopher learned that he was stronger than he knew, he still quickly pointed to coming to terms with the unpredictability and vulnerability of life. His recognition of strength still included the recognition of weakness that other men expressed. Timothy, 45 years old, said, “I'm stronger than I thought I was mentally. And I'm not just saying that. When you get this stuff pumped into you and you sit there. But I just—I can laugh at it. So it's made me stronger. I think it's made me humble, very humbling. And admire the people around you a lot more.” Like Chris, Timothy learned that he was stronger than

expected after going through his experience, but he's also humbled by it. These testicular cancer patients draw on the strength narrative similar to women but are not entirely consistent. Their emphasis on being vulnerable or humbled is also consistent with the other men who learned that they were mortal.

Just as Tim's and Chris's expressions of strength did not sound exactly the same as their female counterparts, Joshua and Kevin extend the strength narrative in a different direction. When I asked Joshua, 29 years old, what he learned about himself, he responded, "I am a warrior, I'm a beast. That's how I feel. I don't think a lot of folks could have navigated it the way I did. I have many family members, many friends that quite frankly I don't think that they would have been able to handle it the way I did. I learned a lot about my character." Joshua's claim that he learned that he was strong is similar to the women's expressions of recognizing their strength but still sounds quite different. Joshua sees himself as a beast, which is much tougher than women's emphasis on asking for help or navigating their experience emotionally. Josh also focuses on being stronger than other people. He was able to do something that he does not think other people could have done. Alternatively, women were surprised that they themselves could do something and did not compare themselves to others. Likewise, Kevin, 39 years old, stated, "That I am one strong SOB, I tell you that. I mean I'm not going to lie to you, I've had doctors tell me the only reason I'm still alive given that I was in such a late stage is because I was happy and in such in good shape. Every doctor that has seen me or done any work on me told me that is the reason why I'm alive." Unlike the women I interviewed, Kevin acknowledges that he was in good shape *before* his experience, which made him stronger throughout. While women explained that they never knew they were strong, these men believed that cancer solidified the fortitude that they had prior to getting sick. Additionally, their

statements of strength are harsher and tougher than the women—Kevin and Josh described themselves as beasts, warriors, and “strong SOBs.” They both survived harsh treatments better than they thought they could have, which helped them acknowledge strength that they might not have seen before, but their strength narratives diverge slightly from the narratives of the women.

Even though strength for testicular patients did not always exactly parallel the women’s explanations of strength, it is still significant that these men discussed strength at all, since most men learned nothing or that that they were more vulnerable. I argue that age plays a key role in understanding why testicular cancer survivors diverge from the rest of the men in the study. The average age of diagnosis for testicular cancer is 33, and the men I interviewed were no exception. Because these men are younger, they are less likely to meet the ideals of hegemonic masculinity than their older counterparts and are less likely to be as financially secure. Authority and control are often linked to age, so as men get older, their power and masculinity becomes solidified. Therefore, younger men are less likely to have a concrete conception of themselves as intrinsically strong. While women are told most of their lives that they are the weaker sex, young men have not fully developed the same sense of power as older men. Thus, younger men are more likely to question whether they contain inherent strength.

Additionally, financial success contributes to feelings of authority and power. Younger men have not accrued the same wealth as their older counterparts and are less likely to feel the same sense of control over their lives. I argue that because testicular cancer survivors are younger, their authority and strength as men is less damaged than that of older men. Their conception of their own masculinity is not as tied to control in the same ways as older men. For older men, especially the white and wealthy middle-class men I interviewed, masculinity is tied to the control that they have felt in their lives at work and within their families. Ultimately,

cancer challenges that control and ultimately damages their sense of self and their sense of their own masculinity. Younger men feel this damage to a lesser degree.

CONCLUSION

As men and women's gender identity becomes less and less connected to the changes to their bodies as shown in chapters 3 and 4, I find that their self-identities are affected in surprising ways. I find that men and women talk about the changes to their sense of self in divergent manners. On the one hand, cancer provides an opportunity for women to recognize their strength and power. On the other hand, cancer challenges men's self-conception as they lose the control that they have taken-for-granted for most of their lives.

Time and time again when I asked women what they learned about themselves throughout their cancer experience they mentioned strength. Even women with recurrent cancer and those that had been in remission for ten years mentioned that cancer taught them that they were stronger than they had ever imagined. Challenging social assumptions that women are inherently weak, cancer provided women an opportunity to see how strong they really were. And strength meant a number of things for these women. Women articulated learning that they were physically stronger than they knew; emotionally/mentally stronger than they had expected; and more capable to do things for themselves and prioritize their own needs.

On the other hand, men stated that they learned that they were mortal and vulnerable through their cancer experience. As opposed to feeling strong, men felt like they beat their cancer diagnosis because they were lucky. Men routinely mentioned how cancer created a sense of a loss of control, a sense of control that I would argue has been inherent and taken-for-grant in their lives as men. This is even more contradictory as men with testicular cancer and prostate cancer have more control over their treatment than women with breast and gynecological cancer

do. This vulnerability led men to become more empathetic and prioritize others. Unlike women, who began to put themselves first, men note that they started to put others first. The fact that both men and women emphasize that these were new behaviors as a consequence of their cancer highlights the different gendered expectations that they faced prior to their diagnosis. Women's newfound strength and advocacy pinpoints cultural expectations for women to be weak and take care of others. Similarly, men's newfound vulnerability and loss of control is indicative of the strength and power that they had taken-for-granted prior to the cancer experience.

CHAPTER 6: THE ROLE OF BIOMEDICAL TECHNOLOGY

When I asked oncologists about the advice that they provide patients undergoing treatment, they frequently emphasized the new and improving medical technologies that could address gendered issues. Oncologists often referenced their role in finding better technology for gender, or often used synonymously, “quality of life” problems. Gendered social issues become medicalized as oncologists prescribe solutions to address the concerns of their patients, whether they agree with their patients’ concerns or not. These courses of action utilize different forms of treatment to help “solve” patients’ gendered issues. While oncologists were clear that treating the cancer was their priority, they also emphasized that once the treatment process had started, a patient’s quality of life and concerns about their gender could be easily solved with medical solutions.

Oncologists’ understanding of the masculinity and femininity concerns of their patients leads them to focus on biomedical solutions that only address a limited number of gendered body issues. Because oncologists conflate masculinity with sexual function and femininity with appearance, they prescribe medical technologies as a means to “fix” men’s sexual function and women’s appearance. Oncologists downplay other side effects of cancer treatment that affect men’s and women’s gendered lives, resulting in some patients not receiving the medical advice nor technology that could help them deal with serious problems with their reproduction and intimacy. However, I argue that doctors’ assumptions about gender and reliance on biomedical solutions cause them to miss the opportunity to have broader discussions about gender with their patients. In this chapter, I show the ways that oncologists discuss specific biomedical technologies to solve the gendered concerns of their patients, and I also reveal survivors’ experiences with these technologies.

As I showed in Chapter 3, patients and oncologists often conflate masculinity with sexual function. As a consequence, oncologists highlight the importance of talking to men about their sex lives and proactively prescribe Viagra. Similarly, as patients and oncologists conflate femininity with women's appearance, and specifically with their breasts, doctors focus on the importance of talking with breast cancer patients about their options for reconstructive surgery. However, both men and women face changes to their sexual function, their physical appearance, and their fertility. In this chapter, I will outline the biomedical discussions about changes to physical bodies, fertility, and sexual dysfunction, and I will analyze how patients address these concerns.

Doctors privilege certain biotechnologies as solutions for gender issues given their assumptions about what masculinity and femininity mean. As a consequence, doctors emphasize Viagra and breast reconstruction as solutions to men's and women's gender identities. In this chapter, I analyze the discourse around breast reconstruction, Viagra, and fertility treatments from both oncologists and patients. Because oncologists use their social understandings to prescribe biomedical solutions, they also potentially ignore concerns from groups whose side effects do not match these social expectations.

First, I look at the changes to women's and men's physical appearance. Women with breast cancer and men with testicular cancer both lose a prominent gendered body part. Oncologists focus on the role of breast reconstruction to resolve women's concerns about their femininity. However, as I showed in Chapters 3 and 4, most women argue that their femininity has not been affected. While some patients decided to utilize these biomedical technologies to resolve concerns about their gender identity, many respondents articulated other reasons for why they did or did not use them that were not connected to their own gender identity. I also look at

the ways that doctors and patients discuss the loss of the testicle. Neither doctors nor patients connect the concept of masculinity with physical appearance, and according to my data, physical appearance indeed is less important for men. As a consequence, men with testicular cancer opt out of additional surgery and decide against the use of prosthetics altogether.

Following the sections on physical appearance, I analyze the discourse surrounding fertility. Given the narrow definitions of masculinity and femininity, fertility is rarely addressed as a concern by the oncologists for women's or men's gender identity. When doctors address fertility, it is seen as primarily feminine yet still disregarded given the supposed success of proactive biotechnologies. As a consequence of the focus on men and sexual function, oncologists brush aside the idea that men might have concerns about fertility, especially with the option to bank sperm.

Lastly, I look at sexual dysfunction. Both men and women face changes to their sexual function, yet sex is seen as primarily masculine. According to oncologists, talking with men about sex is vital because surgery and radiation may lead to erectile dysfunction. Therefore, they actively prescribe Viagra. Patients note that they were preemptively given Viagra and Cialis. However, I argue that men's decisions to utilize these prescriptions were not entirely based on their feelings of insecurity or emasculation. Yet, because oncologists define sex in relationship to men, they overlook the women who experience side effects that greatly affect their ability to have sex.

In this chapter, I argue that because doctors define masculinity and femininity in narrow ways, they downplay other side effects that have drastic effects on patients. Oncologists disregard concerns about fertility for men and sexual function for women. While doctors casually suggest sperm banking and lubricants as solutions to these issues, it is clear from my respondents

that these biomedical technologies are not sufficient, and the conversations surrounding them are sparse. By avoiding these two issues, oncologists fail to offer patients adequate solutions for problems that affect their reproductive and intimate lives.

PHYSICAL APPEARANCE

Given that physical appearance, especially of the breasts, was seen as a primary concern for women's self-identity, oncologists routinely mentioned in interviews that they made it clear to their patients that their breasts could be reconstructed. However, oncologists rarely discussed physical appearance in connection to men. In the following section, I argue that even though oncologists connect femininity with breasts and subsequently reconstruction, the relationship between women's identities, women's appearance, and their decisions to undergo reconstruction is more complex. Women who do not get reconstruction, who do not have bodies catered to the male gaze, can still be secure in their feminine identity. Further, not all women who decided to get reconstruction did so to fix issues with their own femininity. Even women who felt confident in their femininity before they had reconstruction still opted for the additional surgeries.

Following the discussion of women and reconstructive surgery, I discuss the role of prosthetics for fixing the physical appearance for men. While many women felt secure with their gender identity, some still decided to undergo additional surgeries to maintain a "normal" appearance. Men, however, barely considered the idea of having a prosthetic, and most felt like the additional risks were not worth the reward.

Women with Breast Cancer and Reconstructive Surgery

When defining femininity, oncologists focused on issues of appearance (described in Chapter 3). As a consequence, oncologists often emphasize breast reconstruction as the solution to issues with femininity. Dr. Shafran, a medical oncologist, reassures her breast cancer patients

who may have fears about treatment by proposing the possibility of reconstruction. She explained, “Yeah, I tell them that again a lot of things will come back. You know again the breasts can be reconstructed. The hair does come back.”

Oncologists emphasize that saving the breast and maintaining the “normal body” never trump the actual goal of treating the cancer, but reconstruction and medical solutions can be utilized to deal with gender issues. Dr. Sledd explained:

I think when they’re going through the cancer treatment, you know, our focus is, well, let’s first deal with the cancer. You know, then, we will deal with reconstruction. One that there are options. So, it’s not that you would lose your breast and you’re never going to be able to feel—that you’re not going to be able to have reconstruction. So, we make sure that they understand that there are options for them.

While it is hard to know if patients are advised to undergo some form of reconstruction or if they request it, oncologists routinely note that patients *elect* to undergo these surgeries. Dr. Williams stated, “Most women elect to have something started. You know and reconstruction is multiple steps, but to start it at the time of the mastectomy and to go forward yeah, it’s probably maybe one in 100 of my patients that are offered reconstruction that don’t want it.” While Dr. Williams said that almost all of her female patients undergo reconstructive surgery, only about two-thirds of the women I interviewed who underwent mastectomies decided to get reconstruction.

Several oncologists echo that reconstruction is less traumatic for the patient when started during the original mastectomy. Dr. Shafran, a woman breast medical oncologist, said, “They immediately put an expander in so the person, the woman doesn’t wake up without a breast or without—so there’s something in there. So there’s a lot of things that can be done for that, but it is one of the biggest parts of it [address concerns about femininity].” Reconstruction now comes in a variety of forms. Dr. Williams, a breast cancer surgeon, explained the alternatives for some of her female patients who are concerned about foreign material: “One of the things we’re doing

with the reconstructions, we're starting to do fat grafting in smaller breasted women, just liposuctioning fat and then processing it and then grafting it." Oncologists made a point to acknowledge that they always made sure that women knew that they could have reconstruction given their assumptions that a woman's femininity was tied to her breasts.

However, the relationship between women's decisions to undergo reconstructive surgery and their identity was less straightforward than we might expect. Not all women who had mastectomies immediately jumped at the opportunity to have reconstruction. Judy, 70 years old, was diagnosed with an invasive form of breast cancer and decided to have a bilateral mastectomy so she would not have to worry about breast cancer in the other breast down the road. Additionally, the idea of being entirely lopsided bothered her.

They would have to do a mastectomy anyway so I thought okay I don't want to worry about this going on for the next five, six years or whatever. I just want to get a mastectomy, and then I started looking at pictures of people with one mastectomy and not the other. I thought that looks crazy one boob and not the other; and it just bothered me; it's so unbalanced looking. Then I thought well I'd still have to worry about this one I'd still have to go get every six months once you have breast cancer, they want you in every six months. I don't want mammograms partly because of the radiation it adds up it's not good for you. Then just the experience you know where they squash your breast so hard so I thought well I don't want to do that I'll just get a total mastectomy.

The other thing too was if I didn't do a mastectomy, they wanted radiation they're like oh you've got to do radiation. I looked into that and it's all full of problems, and it looked like it can hurt your heart; it can hurt your lungs on your left side, especially. I just thought okay I'm just going to wipe the slate clean.

While she was deciding on her treatment, her doctors also approached her about having reconstruction. Ultimately, she decided against having reconstruction.

I didn't really want it because again, it was like three more surgeries and I think one surgery was all I want to ever do. I didn't want to do it for that reason, and I just figured I'm 70 years old who's going to see me beside me or my husband? I just didn't think I needed it; you know I wasn't going to worry about it, and she didn't push it or anything, so I never saw a plastic surgeon or anything.

Judy noted that she was stronger than she expected and was surprised not to feel less womanly without her breasts. “I was thinking well I just won’t feel very womanly without breasts. It just hasn’t changed my feeling that much like I thought it would. I think it’s been really I feel like I’m a stronger person than I knew I was which is always good to know.” When I asked her about her femininity, she said, “I thought it would that was one of my big worries because I’m a grandmother and I like to take my little grandkids on my lap, and I’m thinking what you know if I don’t have boobs. I don’t know it just seemed like it would be weird, but I don’t think it’s going to matter. Yeah I just think it hasn’t really changed that much.” Judy was concerned that the loss of her breasts would affect how she felt as a woman and as a grandmother, but it ended up not feeling as weird as she had thought. Rather than feeling a loss, Judy recognizes her strength and accepts that she is the same person with or without breasts.

When Judy described looking at her breasts for the first time after surgery, she was surprisingly fine with how she appeared.

But I didn’t think it looked that bad; I thought it would be all you know when I had the biopsy it was so bad looking it was all black and purple and swollen. This never got black and blue or anything it was just kind of my normal skin color with a big scar. The scar looked a little red and stuff but it never really looked that bad honestly. It was pretty tidy. It didn’t really look as scary, I thought it would look awful but it really never looked that bad to me. It’s just kind of like a big old scar going across.

Ultimately, the appearance of Judy’s breasts does not affect her. Judy decided on an aggressive form of treatment, even though she had the option not to have a bilateral mastectomy and chose not to have reconstruction. While she knew reconstruction was an option, she did not want to undergo additional surgeries and did not feel like she needed to have the breasts anyways. The changes to her body were not as awful as she expected, and she is comfortable with the idea that this is her new body. Judy does wear a prosthetic in front of other people.

I won't wear it if I think nobody's coming, and I'm just going to be working in my yard, I don't wear anything. It's definitely more comfortable without it; I pretty much wear it during the day just because I don't want to freak anybody out if they come to the door. I went out to the mailbox once like that and one my friends stopped by in the car, and I'm like "oh dear." If you're in your own yard and nobody's around, I guess it's not a big deal.

Judy feels like the prosthetic is a bit heavy and uncomfortable and really only wears it when she thinks somebody else will see her. Judy opted out of relying on conventional technologies to "fix" her breasts as her own identity moved further and further away from the cultural definition of femininity. Judy made it clear that her own identity was intact. Any concerns she faces about her breasts and her appearance have more to do with concerns that other people might have.

Similarly, Elizabeth, 60, opted for a bilateral mastectomy to eliminate further complications down the line. She also did not want her breasts aging at different rates. Her only concern was for her husband's opinion of her. Elizabeth wanted to make sure that her husband was happy with her decision to have the mastectomy without reconstruction.

Bottom line, he said be healthy, be safe, it's not important you to keep the breasts or to get reconstruction. And I did not want reconstruction. So I just said to him, I mean why would I want two fake breasts and okay, so when I can wear a bra and have cleavage or whatever, but why would I want to do that. I said I really don't care, and I'd rather not have something else in my body that I have to worry about. So anyway the long story short, he was fine.

Elizabeth did not understand why she might want to have two fake breasts, and the idea of having reconstruction just so that she could have cleavage did not make sense to her. She now wears a prosthetic when she is in public, even though she personally feels comfortable being flat-chested.

And in terms of body image, I would be perfectly happy going completely prosthesis free and being—but I am—I mean you know I would be completely, totally flat-chested. Do I go out of the house that way sometimes? Yes, I do. If I wear something scoop neck, whether I have a prosthesis bra on or not, you know if the bra isn't real tight fitting and I bend over, you know it's like a straight shot down to my belly.

So am I self-conscious about that? Yes, I am partly because I also I feel like I don't want to shock someone. It's like oh my God, you know it's concave, there's not even anything there. So would I be very comfortable running around without anything? Yes, you know if I could do that have work and not have people look at me funny or get used to it, I might do it. Am I courageous enough for that? No, I'm not.

When I asked Elizabeth about her femininity she said, "It's funny; my reaction is I'm still the same person. So I don't know that it affected my femininity and it wouldn't change my gender, so I'm still a woman. So that seems like to me it's like a non-issue, I guess you would say." The loss of her breasts did not change how she felt as a woman. Because femininity is most commonly defined by body image, Elizabeth made it clear that she is perfectly content with the way that her body looks and that she has no issue being totally flat-chested. In the instances where she does feel uncomfortable being flat-chested, it is more because of the societal expectation to have breasts and disconnected from her own identity. Outside of other people's feelings, Elizabeth personally feels very comfortable walking around without her prosthesis.

Sandra, 64, was two years out from her diagnosis and had not yet had reconstruction. However, she was planning on getting breast implants in the near future even though she felt fine about the changes to her body. Sandra had decided to have a mastectomy. When talking to her doctors, she came to the conclusion that she may want to have reconstruction, even though it was not her top priority. When I asked her why she decided to have reconstruction, she said:

It was—it was told to me that this is what is—this is what's normally done. It's your choice. Some women say I don't want any more surgery, I'm fine the way I am, I don't have cancer. And I remember that was my first thought that—and my husband and I kept saying we want to make the decisions that are right for my health, not for beauty or vanity. I want to make the decisions for my health.

Her health came first for both her and her husband, and she was not concerned about her appearance when making her decision to have the mastectomy. Her doctors assured her that the reconstruction would not interfere with her health. When I asked her about whether she felt

changes to her femininity, she noted, “You know I kept reading that that would probably happen. And I keep waiting, and it hasn’t happened yet. I think one big thing is because my husband was just such a great person during this whole thing.” She continued, “You know and he kept saying I don’t care what it looks like, it’s doesn’t matter, it’s okay, whatever it looks like.” While Sandra had expected to feel less feminine after her mastectomy, she said that it never happened. Sandra was unclear exactly why she decided to have reconstruction, but she never directly connected concerns about her own appearance or femininity to that decision. For Sandra, her health was her top priority, and her appearance came last, but like many of the men who felt secure with their masculinity but still wanted to use Viagra if they could, Sandra utilized her option for reconstruction.³³ Sandra ended with, “So I don’t have any bad feelings about it all, it was such a good experience for me. And now that I look back, I think you know it’s wasn’t that bad. It really wasn’t. You know breast cancer it’s so scary, but it wasn’t as bad as I thought it would be, it really isn’t.” For Sandra, her experience with breast cancer had not been that bad, even though she had had a mastectomy. She had not had reconstruction immediately following her treatment and was a couple years out from her diagnosis. Sandra eagerly awaited her breast reconstruction but felt fine about her femininity at the time of the interview.

For some women, breast reconstruction was not possible due to their extensive treatment. These women had no option to “fix” their bodies, which no longer conformed to the feminine ideal. These women were more likely to struggle with their feminine identity. Carolyn, 56, had been diagnosed with breast cancer at the age of 40 and had a reoccurrence 10 years later.

Okay, so I was diagnosed in 1997 when I was 40 and that was ductal carcinoma in situ, treated with lumpectomy and radiation. Really seemed like I barely paused in terms of my activity and things like that, but it was certainly a life changing event, I’ll say that. And I made it to almost ten years and was diagnosed again, this time with a much more aggressive cancer, inflammatory breast cancer, which is stage

³³ My impression from Sandra was that it was not about why would she get reconstruction, but more about why not?

IIIC and so that—the treatment was much more extensive. Had chemotherapy and then a double bilateral mastectomy and then radiation treatment after that.

After her mastectomy, Carolyn found out that she unable to have reconstruction because there was too much scar tissue from the numerous treatments. When I asked how she felt about not being able to have reconstruction, she said, “And so again, long-term committed relationship, you know, I’ve never really been a bikini type a gal or anything like that so it wasn’t so much that as just it was just a surprise you know, that it wasn’t even gonna be possible.” When I asked her how she felt about the changes to her body, Carolyn said,

So from that sense, you know, in some ways I feel like my energy’s completely back, most of physical things are back if you look at me from the outside, but inside, if you saw me with no clothes on, the horrible scarring and some of those sorts of things are things that would be an issue between my husband and me for example, but not the outside world. Those have been—those have been tough. But again, I feel like a whiner almost, saying it because in the great grand scheme of things, you know, I’ve been really fortunate I think, even with side effects and stuff because some women have a lot more negative impacts than I’ve had with the treatment.

Unlike Sandra, Elizabeth, and Judy, Carolyn struggles with her femininity. She mentioned that coping with the scarring and the changes to her body were tough, even though other people could not see it and how though that had been. But Carolyn feels conflicted about feeling insecure and grateful. Carolyn is grateful for the support of her husband but still feels less attractive than before. “It’s more on my side I think than his side I guess is what I’m trying to say. So I don’t think it is an issue for him but it’s an issue for me.” Carolyn is not sure if she would have chosen reconstruction, but she was surprised when she did not have the option. Whether the reconstructive surgery would have helped Carolyn feel better about the changes to her body is unclear, but it is clear that she has not fully come to terms with her new appearance.

Oncologists generally point to reconstruction as the solution for femininity issues. However, many women do not or cannot receive reconstruction. Some women remain secure in

their feminine identity despite not having a normative body. Others find it difficult to maintain a strong feminine identity without the appropriate body. By placing so much emphasis on reconstruction as *the* technology that could “fix” gender issues for women, the medical establishment disadvantages those women who cannot receive this procedure, leaving them to grasp for other ways to bolster their feminine identity.

Even for the women who do undergo reconstructive surgery, the relationship between their gender identity and that decision is not always obvious. Given that reconstructive surgery is seen as a solution to women’s femininity, we assume that only women with femininity issues would undergo five to six additional surgeries. However, even women, like Sandra, who felt secure with their identities still opted for reconstruction. Cynthia, 48, was diagnosed with stage IV breast cancer and underwent a very aggressive treatment that included a bilateral mastectomy. Within weeks of her diagnosis, Cynthia had to decide if she wanted to have reconstruction. She noted:

So what actually happened so, in that two weeks before I went into surgery, I had met with my oncology surgeon and she said okay, well are you going to have reconstruction? And I asked you know well what—you know what would—why wouldn’t I—why would I not want to have reconstruction? Is there a reason that I wouldn’t want to? And she said no, there’s no reason whatsoever it doesn’t change anything, you know, I said okay.

So both surgeons were there when I had surgery. And my expanders were put in right when I had my mastectomy and they were even expanded a little bit. So when I came out of my original surgery, I wasn’t concave. I was like tiny, tiny, tiny little bumps. And then—so from that I healed from my surgery, I expanded out until October, and I started radiation in October. So they expanded me fully before I had radiation.

Both the plastic surgeon and the oncology surgeon told Cynthia that she would be a good candidate for reconstruction and that there were no medical reasons not to proceed with reconstruction. Her reconstruction began the day of her bilateral mastectomy. When I asked why

she decided to have reconstruction, she said:

I had made a decision for myself when I got a divorce that I wasn't going to pursue any relationship until later. And in my mind, I thought yes, I looked like Humpty Dumpty, but like I think I would feel more confident going back out at some point if I somewhat resembled what a woman is supposed to look like. You know this is going to be a stranger, this is not going to be someone who loves me for who I am, this is going to someone who I have to attract initially and so you know I said why not.

Again, it had—if that part had ever been one more thing to consider that would make my recovery, that would jeopardize my recovery at all, I would have—it would have been very easy for me not to do it. But I kept being told there's no—you know it doesn't matter one way or the other. And so I was like well then of course I would do that.

All of her doctors told her that there was no drawback to reconstruction. As a reminder, reconstructive surgery includes a number of major surgeries. Any major surgery, especially those that involve anesthesia, comes with risks to the patient's health. Because Cynthia wanted to find a new partner down the line, she decided to undergo the additional surgeries. Throughout the interview, Cynthia was clear that she did not feel a sense of loss or damage from her surgeries. She was still able to find men to date who were not concerned about her "Humpty Dumpty" breasts. She was adamant that her femininity had not changed. I mentioned Cynthia in Chapter 3 when she said that she was amazed at how different her breasts looked yet not upset or horrified at all. She noted that she experienced "none of the sense of loss that a lot of people say that they felt at all, just kind of awed by it." When we talked about how she felt about her new breasts, she said, "They're just what they are, and I don't even notice, like I don't even remember what it was like before. It's just me, like I just feel normal this way now, and I don't even know what that was like anymore." Cynthia's treatment was very difficult, and chemotherapy took a lot out of her, but she was consistent that her feminine gender identity had not been damaged from the loss of her breasts. While she did have reconstruction, Cynthia likely would have felt the same way

with or without her new breasts. Her attitude towards her breasts is disconnected from her own sense of self. In fact, she might have preferred to have significantly smaller breasts. “Like kind of immediately it just was wow this is different and like I loved it, I loved, I’m a little sad that I ended up back as big as I am now, just because I loved being teeny tiny, I just thought like dude, this is like fabulous and that was great.” She asserted that she loves her body and is more amazed by the transformation than concerned with its disfigurement. For Cynthia, her reconstructive surgery did not alter how she feels as a woman. Rather, Cynthia loved her body even prior to the reconstruction but opted for reconstruction for other reasons: 1) because her doctors encouraged it and 2) she felt like men might not immediately find it attractive on the dating scene. Ultimately, Cynthia did not choose reconstruction because her own sense of self was damaged.

Similarly, Felicia, 38, decided to have reconstruction during her mastectomy. She was clear that it was her decision but that she felt compelled to have reconstruction to make things more seamless for her very young twin boys.

I was, it was really in a lot of ways my decision to have reconstruction in the way that I did but it was partially about them also. Because I couldn’t leave home with a breast and come back without one with them being so aware and cognizant of what’s happening on me, that just would have been, that would have been really odd.

At 38, I thought that it would have been really odd for me not to have a breast so it was also important for that perspective. They were really impacted by it a lot and just dealing with where they were as three-year olds.

Being diagnosed at a young age and with small children, Felicia felt like it was important to keep things the same, as much as she could. She worried that coming home from the hospital entirely flat chested would alarm her already anxious sons. Her decision to reconstruct was partially for her and partially for her children.

We also had to keep in mind what was going on for us at home. I knew well, like I said earlier about reconstruction, I knew that I was going to have reconstruction.

There was no question. I needed it for me; I needed it for the boys. At that time, I think I needed it more for them. I mean I thought that I would have just felt really odd not having a breast.

Before she had her surgery, she knew she would have reconstruction because it was important to her and her children. Felicia was clear that her primary concern was consistency. Even though Felicia decided to undergo the reconstructive surgery, she was still very clear that her own identity was no longer connected to her breasts, “It definitely changed in many ways it heightened my awareness of myself. My acceptance and belief in the fact that my femininity is more than just my hair and just my boobs.” For Felicia, having a mastectomy and subsequent reconstruction allowed her to see that she did not need breasts to be who she was letting her to feel more secure in her feminine identity in a surprising way. Her reconstructive surgery provided her the space and security to realize that her femininity did not rest on her appearance. “I was able to find a lot of my own power and my own strength and able to trust myself in that way.”

However, there are other people, like Karen highlighted in Chapter 4, who felt that their femininity was directly connected to their breasts. Karen’s breasts had been important to how she saw herself her whole life. Her mastectomy really felt like a loss, especially as a single woman. “I knew the one choice was to have a double mastectomy, *maybe not even to have reconstruction. And it’s too much a part of my femininity and my view and my self-image to do that.* So you know obviously I consider breasts to be part of my femininity and my appeal and feeling attractive to men, and I think that’s magnified because I’m single” (emphasis added). Karen recognized that some women decided against reconstruction, but she did not consider that as an option because of the importance of her breasts to her sense of self and image. While Karen knew that she had the option not to do reconstruction, she never doubted that she would do it,

even though she might not have wanted to go through all of the additional steps.

Even like I've seen my friend who had her nipple replaced after her two lumpectomies and mastectomy and I'm even debating whether I'll even—because that's another surgery afterwards, and you know I'll wait and see, you know, you can do it at any time. That's what the doctor said so because I told him—I go, I don't even think I'm going to do that, you know, it's like why? Like—and hers, it almost like fades away, you know, it's like it's almost like not a nipple anyway, you know. Like why bother. Then I'm like God, I spent my whole life trying to be sure my nipples weren't showing through my clothes so why put one on? I mean there's a practicality to it too, you know. I don't have to worry about whether one shows.

In the beginning through the lumpectomies it was like I still had that hope, you know, that my body would basically look the same, you know, but now I don't. You know it's kind of like—it's a letting go. I feel like this has been a constant thing of letting go of pieces and parts and whatever, and you have to come to grips with how important are they, you know, the different aspects of things, right down to okay, well how important is the boob? Okay, well all right, I've given that up. Well how important is a nipple? What's it worth? Is it worth going through all this? Probably not, you know. So that's kind of the way it goes.

While Karen was clear in the interview that her femininity was closely connected to the appearance of her breasts, she was beginning to slowly let go of the expectations that her body needed to look the same. Her breasts were important enough to have reconstructive surgery, but she drew the line at having the nipple reconstructed. For Karen, having a nipple was not worth the extra surgery and might even be more practical. Unlike Felicia and Cynthia, who were clear that their femininity was intact, Karen still felt a sense of loss as a single woman. However, Karen was not willing to undergo surgeries at any cost to maintain her appearance.

Oncologists point to reconstruction as the “solution” for issues about femininity—focusing on the relationship between femininity and the body. However, the connection between women's identities, their bodies, and their decisions to have reconstruction was more complex. Some women, such as Judy and Elizabeth, opted out of reconstruction and maintained a positive attitude towards their own body and feminine identity. Similarly, some women, such as Sandra,

Cynthia, and Felicia, opted to undergo reconstructive surgery even though they felt confident with their femininity. Ultimately, reconstruction did not always “fix” women’s concerns about their femininity and their bodies; Karen received reconstruction but remained insecure about her appearance and her feminine identity, especially as a single woman. Therefore, counter to oncologists’ predictions, reconstruction’s role in solving the issues surrounding femininity is more complex for breast cancer patients. Reconstruction’s inability to bolster all women’s feminine identity demonstrates that patients’ gender identities do not solely rest on the body, but instead are much more complicated.

Testicular Cancer Survivors and Prosthetics

Physical appearance was never connected to masculinity in my discussions with oncologists. However, when I asked questions about the loss of the testicle, they did occasionally mention that testicular cancer patients who had body image concerns could have implanted prosthetics. For example, Dr. McCarthy said, “There’s a—obviously you lose one of your testicles and for a few guys that’s an issue, just a body image issue. You can put in a prosthesis, although I would say the majority of guys don’t bother. That doesn’t bother them that much. As long as you’ve got one testicle left that’s usually adequate as far as testosterone generation and long-term health.” Dr. McCarthy made it clear that if men were concerned, a prosthetic works, but most men do not care about the loss of the testicle. This is in stark contrast to what oncologists say about the loss of the breast and their role in fixing bodies. Men and women both lose a prominent gendered body part, but the idea that this would only affect women is significant.

Like Dr. McCarthy alluded, none of the testicular cancer patients I interviewed underwent additional surgery to have a prosthetic testicle. As I showed in Chapters 3 and 4, most

of these men's masculine identities remain intact despite the loss of the testicle. These men's decisions to forego the biomedical "solution" for a body that no longer fits the male norm demonstrates the insignificance of the physical appearance of the testicle to men's masculinity. Men are secure with the changes to their physical body in a way that gives them freedom and privilege to forego additional surgeries for a prosthetic. Unlike women who undergo extensive reconstruction (even if they do not feel all that damaged by the loss of their breasts), most men did not even consider the idea of a prosthetic testicle. This finding is consistent with other studies that find that most men choose not to have prosthetics (Chapple and McPherson 2004).

When I asked Timothy, age 45, if he would have considered a prosthetic, he said, "I don't want to be operated on again. I mean it's the least of my concerns." The appearance of his genitalia was not a primary concern for Timothy, and the risks of another surgery outweighed the benefits of conforming to the normative male body. Similarly, Robert, 30 years old, explained that the payoff needed to be larger before he would consider another risky surgery. He said that he might have considered some sort of prosthetic or additional surgery if he had lost both testicles, but not just one: "If it were both of them I might consider it but because it's just one it seems like it's more risk and hassle than it's worth." For these men, the loss of one testicle was not a large enough gendered disruption to warrant the use of the biomedical solution that was available to them.

Other men emphasized that the change to their male body did not affect their masculine identity; therefore, they did not feel the need to receive a prosthetic testicle. Joshua, 29 years old, said that he did not want to have a prosthetic because he was not insecure about the loss of the one testicle. Before he had one testicle surgically removed, Joshua was concerned about how his genitalia would look after the procedure, and he had started talking with his doctor about a

prosthetic. However, he changed his mind after the surgery. When I asked if he would want a prosthetic testicle, he answered:

No, actually, not right now, no. I'm good. I'm feeling fine. I'm not insecure about it. I'm not uncomfortable with it. I mean at the time I was thinking about it just from a, you know, I wanted it to look the way it looked. But no, I'm actually—it's fine. No, I actually have not continued that conversation with my urologist about it at all.

Who knows, maybe in the future, but I haven't really thought about it. I like having room for my good one. I mean it's not like, you know, it's not like it's public, like only like one other person in my private life, like my fiancé is the only person who has seen it.

Joshua realized that the changes to the body did not make him “insecure”—neither about his body image nor his masculinity. In other words, he did not need a biomedical solution to feel secure with his masculine identity.

Even younger single men, such as Nicholas, at the age of 23, also decided against any additional procedures. Nicholas told me:

My sister had asked me a lot about that and before she asked me about it—I honestly never thought much about it as far as like having one testicle. It never bothered me. My mom had thought I'd want to get a prosthetic put in, but I told her no, I don't want that. *I never wanted one [a prosthetic] just because I don't know, it just never occurred to me that it [having one testicle] affected my manhood or masculinity or anything.* Yeah, going into it I just knew I wouldn't want one and it never actually came up like with the doctor or anything. He never asked if I would want one or not. I wanted to avoid more surgery around the groin area so I just really didn't see a point in getting, you know, a fake one put in me, but no, no doctor ever actually directly asked me about that. I guess it's something I would have had to pursue myself if I had wanted one. (emphasis added)

Nicholas directly said that having one testicle does not affect his masculine identity. He is clear that his masculinity is secure despite not having a body that conforms to the normative male body. Like Nicholas, testicular cancer patients were clear that the loss of one testicle did not have an effect on their masculinity and that they did not feel insecure or self-conscious about the loss. Because they did not feel concerned about changes to their masculine body, they all decided

against an extra surgery that could pose additional risks. For men with testicular cancer, the risks associated with “fixing” their male bodies outweighed the potential benefit of changing “the way it looked.”

One of the strategies used by testicular cancer patients to cope with the changes to their bodies and their cancer experience is to make light of the situation.³⁴ Men do not get the prosthetic because they are secure in their masculine identity despite having an altered body. Testicular cancer patients were quick to note that it is easier to laugh about the fact that they only have one testicle than to feel self-conscious about it. Jeffrey, 43 years old, said that his cancer and surgery does not affect him at all because he can joke about it.

It didn't affect me at all really. And I never thought about it until friends started saying stuff about it. I guess my thing is just to get over it. But I do joke about it a lot just like when you did that yesterday saying you're going to postpone it, I said you're busting my ball. I make jokes like that all the time, and it's funny to see how some people get uncomfortable with it. Like no, it's not funny to laugh that you lost a testicle. It's like it doesn't bother me and I made the joke.

He continued,

At first they weren't teasing me about it. They were more asking, “well how do you feel about losing your testicle?” and like I said it never occurred to me to be bothered by it. Like I said it might have been different if I had a double orchiectomy. But just with the one it never bothered me. And then the first email I sent out after I told my close friends, I sent an email out to all my friends, and I said—at the very end of it I said I'd give my right nut to be done with this, and then everybody realized that it was still the same old Jeff. I was still going to joke about it. And so then that's when they started joking about it back with me and made a joke about being half the man and all that stuff.

He followed up by telling me a story of when he and his wife planned a prank on his co-workers by bringing a fake slimy amputated testicle stapled to a flyer to a retirement party and pretending it was his. Jeffrey's ability to make light of the situation made it easier for him to laugh with his friends and co-workers about what he was going through. He repeatedly emphasized that his

³⁴ This is consistent with Gordon (1995) who argues that men with testicular cancer joke to avoid confronting their feelings, handling their emotions “like a man.”

masculinity is not tied up in his physical appearance or the loss of a testicle. He continued, “I don’t think there’s a masculinity tied to it. I mean—I don’t know if I should tell you this or not. Since then we decided just on a whim on vacation to go to a nude beach and it didn’t bother me at all to be naked around other people only having one testicle.” Jeffrey is able to maintain his masculinity by laughing at something that could challenge his masculine identity. His guy friends joke about not being man enough, but being able to take the joke and laugh at himself reinforces Jeffrey’s masculine status. “In fact a lot of times, you know, especially when guys get together they’ll say you don’t have the balls or something, and then he or somebody else will say well Jeff doesn’t.” Laughing about only having one ball helps Jeffrey maintain a masculine identity among his friends, and he does not feel threatened by remarks about not having the balls to do something risky. These men use humor to maintain their masculine identity even though they do not have a normative male body, making the biomedical technology of the prosthetic unnecessary.

When I asked Daniel, 29, about whether he considered having a prosthetic testicle implanted, he responded:

I heard about those. I don’t know if my urologist mentioned it but I don’t know how I heard it... I never really considered it. I mean I wouldn’t spend money on something like that.

And I think like it just—I guess it’s my sense of humor but having a fake ball is almost more absurd to me than just having one. But like I said my sense of humor about like the question about masculinity, manhood and *you know having one ball versus two, I’m not insecure about that* because it’s just—for me it’s sort of a joke, right. It’s not something that I could control so why—I mean why worry over something like that? I’d rather just, you know, take pleasure in it in a weird way. And that’s where the humor comes in.

Daniel uses his sense of humor to manage the changes to his body. He explained that he would not waste money on a prosthetic because his masculinity is not tied up in the loss of a testicle.

Similarly, Matthew, 33 years old, felt more masculine by laughing at the loss of his testicle:

No, it has not changed at all. I think a lot of that is our, you know, that sense of humor and we, you know, it's something of course, you wouldn't like to joke about, but honestly I don't take that as any kind of personal affront. I say I'd rather be the way I am now than not be here at all, so it's—to me it's funny. I feel maybe more masculine in a way. You know if anybody makes, you know, lighthearted jokes about it to me like ball jokes and I'll say you know what, I only need one. Because I just, you know, that's how I feel. So other than that, you know, you guys need two and I'm better off. So that hasn't affected me that way at all.

For Matthew, having only one testicle makes him feel more masculine because he does not *need* two. Matthew's sense of humor helps him maintain his masculinity through something that may have impacted his gender identity. Similarly, William, 36 years old, said, "That hasn't really changed at all. I'm the first guy in the room to make a joke about the fact that I only have one ball these days. I don't feel any less virile than any other male does. It really hasn't affected me that way." Similar to Matthew, Jeffrey, and Daniel, William retains a strong masculine identity by making light of his situation and joking about the fact that he only has one ball.

I argue that men with testicular cancer use jokes and humor to mitigate any potential damage to their masculine identity that they could feel as a result of losing a testicle. Instead of going through additional surgery to have a prosthetic, testicular cancer patients use humor as a way to manage the permanent loss of the testicle. Consistent with oncologists' assessments, men are less concerned about the ways that their bodies look. Instead undergoing additional surgeries for a prosthetic implant, these men make fun of the fact that they now only have one testicle. Testicular cancer patients feel confident in the changes to their bodies and do not connect the

change in their appearance to their own masculinity. As a consequence, none of them elected to have the prosthetic.

The idea that a fake testicle is more absurd than having just one stands in stark contrast to the idea that women automatically opt into undergoing six to seven additional surgeries for a fake breast. Because the physical appearance of the breast is seen as the foundation of women's femininity, reconstructing the breast is the central focus for oncologists. However, neither doctors nor patients connected the physical appearance of the testicle to men's masculinity. This highlights a key difference between the social expectations of men and women. Men are bestowed a privilege that allows them to feel secure with the loss of their testicle by making light of this loss. Contrary to women, men are able to easily dismiss the idea of a prosthetic.

FERTILITY

The treatments for testicular, gynecological, and breast cancers can all lead to the loss of fertility for younger patients. While it is less common for women to be diagnosed with these cancers at a younger age, testicular cancer primarily affects young men. Even though sterility is a major side effect of these treatments, oncologists rarely connected femininity or masculinity with fertility (as described in Chapter 3). Given that fertility was not connected to masculinity or femininity, and given the available resources and preventative biomedical solutions, oncologists often stated that it was not a major concern. And when fertility was brought up, it was often connected exclusively to women.

In the following sections, I show how oncologists presume that the inability to bear children is not an issue for women's femininity, particularly given the biomedical technology available to harvest eggs. I argue that oncologists' narrow definition of femininity and their emphasis on biotechnological solutions could have negative affects on sterile pre-menopausal

women. A similar phenomenon also occurs for men. Oncologists dismiss fertility as an issue connected to men's masculinity and assume that sperm banking would resolve such concerns. However, I show that banking sperm does not and cannot assuage men's anxieties about sterility.

Women and Fertility

In discussions with oncologists, the loss of fertility as a side effect for pre-menopausal women came up routinely. However, women's potential concerns about fertility were swept aside as oncologists emphasized the increasing number of fertility treatments available to these women. When I asked about the advice that oncologists give women about femininity, they almost always jumped to discussions of breast reconstruction. It was only when I followed up about concerns with fertility that these biotechnologies were addressed. When I asked Dr. Yarborough about the advice she gives her female patients if they are having a hard time coping with the loss of fertility, she said, "Well you know thankfully in 2012 depending—I'm trying to think of the scenario that fits what you say because, remember, now we can egg harvest and all of that stuff." For Dr. Yarborough, these treatments effectively solve the loss of fertility, so she believes that patients no longer have a reason to be concerned about this issue. Notably, this differs from oncologists' discussions about breast reconstruction. Breast reconstruction and fertility treatments both address two major issues that women might have, but doctors only imagine that women would have difficulty with the removal of one or both breasts. They do not imagine that women might have difficulty with the loss of fertility. This difference can be traced to oncologists' conflation of femininity with appearance; since oncologists believe that appearance is a much greater concern than fertility for women, they assume that the existing fertility treatments adequately address any concerns women might have. Similarly, Dr. Richardson stated:

The good news is the radiation for breast cancer doesn't make them infertile but occasionally chemotherapy can if they need chemotherapy... For women now it's possible to harvest eggs, so there's a lot of hope now for women who are put into menopause by either chemotherapy or if they need radiation to the pelvis. If they have radiation of the pelvis, they are not going to bear a child in their own uterus, but they can still harvest eggs and use a surrogate. There are a lot of options now that didn't exist before.

Dr. Richardson explained the many technologies that are available to “solve” fertility issues for women. Dr. Richardson did acknowledge that these treatments do drastically change the way that women would be able to have children, but she still did not discuss how these changes might pose concerns for patients or impact patients' femininity.

Other oncologists more directly noted that they do not view fertility treatment as related to patients' femininity. Dr. Soper, a medical oncologist, stated that fertility is not a concern of femininity for his patients: “Well, fertility and femininity—the overlap is actually relatively small because fertility is something that we address very proactively. So, if a woman is going to be receiving chemotherapy and she's of childbearing age, she's offered a consultation, like an emergency consultation with our fertility doctor.” While oncologists connected fertility to women, they believed that if their patients are given all of the available resources, fertility disappears as an issue. Oncologists view fertility as less important to women than their appearance, so they believe the available technology is adequate to fix this relatively minor problem that does not affect the core of who they are as women. Doctors do not really see fertility as a part of femininity, and the existence of treatment is just an additional reason why they believe it should not be a concern for women.

However, the loss of fertility likely impacts women and their femininity more than oncologists presume. I only interviewed one gynecological cancer patient whose cancer treatment caused her to lose her fertility before she had children, and she felt that this loss

damaged her femininity. Recall Jennifer, from Chapter 3, a 44-year-old ovarian cancer survivor. Jennifer was in a lot of pain and had an emergency surgery. She made it clear to her surgeon that she did not want a full hysterectomy, but during the surgery he consulted with her father because it looked like the cancer had spread. She woke up to find that both ovaries had been removed.

Yeah, it was probably one of the most traumatic moments of my life, I—you know from being just so sure of the fact that – and you know we had talked to my doctor, Dr. Silverman, we had had a pretty good talk about I didn't want to have everything removed, and you know—I mean I'm not of child bearing years, but you know some day I still thought I wanted to maybe possibly have a family. And you know I just really didn't want to have the full hysterectomy if the tumor was right next to just one ovary, that's all I wanted. So I know that he – I was later told that he came out in the middle of the procedure and talked to my family in the waiting room, and said look you know this is—this is the situation, we think it's cancer, we think it's you know malignant, you know what do you want to do, because and that told me that she really—you know she really didn't want to have a full hysterectomy. And you know it's a hard decision, I know but my father said to him, “you know if she was your daughter, what would you do?” And that's when he said, “I would clear everything, I would leave no trace of cancer there.”

Jennifer was surprised to find out that she had had the full hysterectomy and even more shocked when she was being discharged from the hospital and told that she needed to start chemotherapy. Jennifer was over a year out from her diagnosis but still felt like she was recovering from her experience.

I think I'm still kind of going through the journey. There are times when I wake up and feel a total sense of loss and sadness. And other days, I feel happy and grateful and you know ready to conquer new things. But yeah, you know I think it's still something that's evolving and the situation with not being able to have children of my own has been tough.

Because it was interesting, I was telling the therapist a couple weeks ago, you know you think you've—you think you've surpassed that, and you made a lot of – how do you say it, like I feel like I sometimes have put that behind me, and emotionally have grown. And then something will trigger me and set me back, and the other day I was the doctor's office, they've prescribed what's called an e-string, which helps because with the menopause, you have just a lot of dryness. And you know not a lot of moisture there, and so you know just sexually it can affect your sexual life.

So they gave me this thing called an e-string which is kind of a circular thing that you insert every three months and it has just a little bit of estrogen. So it's very localized. So I went to have that checked and it was an ob/gyn practice and so I came in the room was full of pregnant, pregnant women and I remembered just starting to feel kind of panicky, like oh my gosh, I don't know if I can handle this. And I remember being taken back into one of the exam rooms and when the nurse asked me when was the first day of your last period, I just like triggered everything for me, because I had to say well I don't have periods any more, I've had a hysterectomy and when I say just like the tears started flowing. So little things when you feel like you've surpassed it and then little things will trigger it again. So that's why I think it's still—you know I'm still on a journey trying to you know get where I feel like a sense where it's feeling confident and assured emotionally.

Jennifer was very clear that losing her fertility is an issue that she has not been able to fully cope with. She struggles with the constant reminders, such as the scars on her belly or seeing pregnant women at the gynecologist office. When I asked what she meant by loss at the beginning of her story, she said, “Well the loss of losing my fertility, I think is huge for—was huge for me.”

While the oncologists have faith that the medical solutions resolve women's concerns about fertility, Jennifer was unable to utilize the technologies because of her emergency surgery.

When oncologists point to fertility treatments to downplay the loss of fertility, they overlook the patients who are unable to receive these proactive interventions for a number of reasons (aggressiveness of their cancer, etc.), and young women diagnosed with ovarian cancer often do not have these options. There is no doubt that many of these patients would have concerns about their fertility in connection to their femininity. However, according to the oncologists, fertility issues can often be proactively addressed with the new technological advances. Yet, these technologies likely do not fix women's concerns with fertility or address how women's femininity is affected by the loss of their ability to carry and give birth to a child.

Testicular Cancer Patients and Sperm Banking

Oncologists almost never mentioned fertility in conversations about masculinity, as

discussions about masculinity immediately focused on potency and sex. When fertility came up in the interview, oncologists immediately brushed it aside as a problem that doctors had already solved with sperm banking. On the rare occasion, doctors did acknowledge that their testicular cancer patients face sterility, and I followed up about whether patients had concerns with fertility. Dr. Richardson stated:

So there's always a balance between the urgency of getting someone on treatment and the necessity or the urgency of preserving fertility... So there are issues of sperm banking in men for example, not the prostate cancer, they are typically too old to worry about that, but for the testicular cancer patients there are issues of sperm banking.

Similarly, Dr. Hans, an oncologist, explained:

Most commonly that [fertility] comes up in our young patients with a potentially curable cancer. So, sperm and egg preservation, that has to come up. It's part of the informed consent for treatment. So, most of my patients will try to quickly get that part figured out and get egg or sperm banking done pretty quickly so that they can start their treatment. So, that just becomes something that they have to decide very quickly about and get done. So, most of my young patients, who even remotely think that they're going to want to have kids will do that very quickly.

Dr. Hans was clear that conversations about sperm banking and egg preservation are presented along with treatment options because fertility can be affected by surgery, chemotherapy, or radiation. These doctors are optimistic about the success of sperm and egg preservation and note the growing number of technological solutions.

Given how infrequently oncologists discussed testicular cancer and fertility, I was surprised at how many men brought up concerns or fears about the loss of fertility. Testicular cancer patients routinely mentioned that their urologist told them at the time of their diagnosis that they should bank their sperm. It was common for testicular cancer patients to mention that their doctors suggested banking their sperm in a matter-of-fact manner. For example, Michael, 43, said, "He was very clear with that piece of it. He recommended that if you want to have more

kids, then he recommends you can do the banking all that kind of stuff.” And many men noted that their doctors immediately asked about whether they wanted to have children when giving them their diagnosis. Michael continued, “It’s funny now that you mention that even when I first met with the urologist, I think one of the first things said was like do you think are you planning to have more kids. That wasn’t even about the diagnosis of cancer it was like, ‘oh that’s funny why would he ask me that?’” Matthew, 33, shared a similar experience.

So then the doctor came in and he checked me out and the way he kind of broke the news is he asked my wife “do you guys have kids?” And she went, “yeah, two.” And he’s like, “do you want any more?” “Well we don’t have a girl.” “You might want to think about, you know, sperm banking” and then that’s kind of how he got into the whole conversation. I found out what I had and pretty much the scenario I had to go through, the surgery and get that scheduled. So it was kind of a whirlwind event. It was kind of more shocking than anything because somehow I didn’t expect that to be the outcome.

Sperm banking was linked with testicular cancer diagnosis or even suspicions of testicular cancer.³⁵ Jeffrey, 43, also told a comparable story.

Yeah, that was kind of funny because at the same appointment he said, you know, “we’re 99 percent sure it’s cancer, we’re doing your surgery on Thursday, you probably won’t have any problems with fertility but you need to go immediately out of this office and over to the fertility clinic and leave a sample just in case.” And you know, that doesn’t really put you in the mood just getting diagnosed with cancer and told you’re going to have surgery and now you’re supposed to go get in the mood to leave the sample so it was an odd day to say the least. So we went that day. We didn’t have a choice because we were doing the surgery so fast so I went that day and they had me come back two days later right before the surgery and leave another sample.

Jeffrey joked that being told you have cancer does not really put you in the mood to donate sperm, but it was important enough for him to do it. Testicular cancer survivors routinely note that their oncologists nonchalantly told them that their treatment could make them sterile and recommended sperm banking if they wanted to have kids. It appears that urologists try to manage

³⁵ Some men had their testicle removed before they knew it was testicular cancer because occasionally the tumor is not biopsied until it has been removed.

any concerns about fertility by immediately recommending sperm banking. Therefore, because banking sperm is the solution, oncologists essentially view fertility as a non-issue.

While oncologists ignored the possibility that fertility might affect men's masculinity, some of the men I interviewed found out that they were no longer fertile and had a very difficult time as a consequence. Nicholas, who was 23 at the time of our interview but 19 at the time of his diagnosis, was assured that his fertility would come back post-treatment.

At that time I really didn't think much of it because they said it was a really low chance that I'd actually be infertile so I would just bank the sperm and then a year later probably just have it thrown out. I remember the process of banking sperm was a very weird, a very awkward—there's only one fertility clinic in Lexington and it's at Central Baptist Hospital and it obviously caters towards women. Like their logo is of a woman holding a baby and all the colors are pink and if you go on the website it's almost all about female fertility. Like even the section on males is actually like under the female section under partners basically.

So they don't really advertise much about their sperm banking and semen analysis and all that. But it was just really weird having to do that at 19, especially considering I didn't think about having kids, like if I wanted kids or anything. I had no idea.

Nicholas continued, "They recommended I bank sperm which I did but they really didn't think that that was a high possibility at all. But it did happen. It's been almost—it's been three and a half years and I'm still infertile so it's probably permanent but they don't know that for sure but most likely." When I asked Nicholas about the fact that he might be permanently infertile, he said:

It bothered me a lot more than I thought it would. When I was 19 and did the initial banking and they told me it could make me infertile I wasn't that worried about it just because I had never thought about having kids really and I really didn't think it was going to be a problem, but about two years after the chemo is when they recommended I do the semen analysis. It usually does makes you at least temporarily infertile but in about two years you'll know if it returned to normal or not and so that's when I found out that it hadn't and I took that a lot harder than I ever thought I would.

Like I never cried when I found out that I had cancer, you know, that first time or

when it recurred but I really cried a lot when I found out that I was still infertile. And I didn't really know why. Even still at that point and today I didn't really have any idea if I would want kids and I'm single so it's not like an immediate problem or anything and I just felt I can have kids technically with the banked sperm.

Nicholas did not think he would actually become sterile from his treatment, and at the age of 19, he could not imagine how it might affect him. When he did find out that his sperm count had not returned, he was more upset than he had been throughout the entire experience. Nicholas continued to explain how isolating being sterile was for him.

But it still can be very bothersome and it feels—it's a very isolating thing because most people don't think about it, especially at a young age. And so, you know, I still have family members or people ask you, you know, when are you planning to have kids or are you going to have kids or do you want kids? And it's just an awkward thing like "well I really don't know and I don't know if I can have kids. So thanks for reminding me." Even my parents sometimes forget. You know my dad, it was several months he made that typical joke of saying "oh I wish we had grandkids out here" and I told him, you know, "you have a better chance of producing kids than me so if you want kids you should do it yourself."

And my sister was talking to me about her wanting to have kids because she's about two and a half years older than me so she's 26. She's talking about when they're planning to have kids and all this stuff and how she'd like three at the most. She wants one boy, one girl, and you know I'm standing there like "that's nice for you, you can plan for that when some people can't even consider that an option." And it was just kind of weird and again just knowing that she obviously had completely forgotten that, you know, that happened for me and it's still going on.

It's just a really weird feeling. Sometimes when I'm around kids even now I get so emotional just knowing that—it's almost like seeing a future that could have been but never will be sort of thing, and it's just—it's really weird. Again it was something I never thought would bother me that much, especially when I was 19, but it's been the thing that's bothered me the most out of all the things that happened.

While Nicholas may still be able to have children with the sperm that he banked before his initial surgery, he is still troubled by the fact that he may not be able to have children "naturally."

Nicholas's experience donating his sperm at the woman-centered fertility clinic and his

subsequent experiences with friends and family have left him feeling isolated and uncomfortable. Mundane conversations have become reminders of his infertility. Nicholas is more upset and bothered by his loss of fertility than he had expected when they told him it was a possibility. While Nicholas does not connect fertility to masculinity, it is clear that this loss had a greater impact on his own identity than the loss of a testicle or potential changes to his sexual function. Even though Nicholas had banked sperm, this technology has not resolved the issues that he faces and his concerns about having children in the future.

Like Nicholas, Daniel, 29, banked sperm and was still sterile after treatment. While Daniel's masculine identity was more intact than Nicholas's, the biomedical technology of sperm banking does not seem to be responsible. Instead, it appears that, from the start, Daniel's masculine identity relied less on his fertility.

Part of what worried me about the surgery, the RPLND was that there's—I can't remember even what it is but there's a risk that the surgery will cause you to—it's called—oh what do they call it? Retrograde ejaculation. So when you have an orgasm instead of ejaculating it could go back into your bladder. So and this was—they called it a risk of this surgery that could cause retrograde ejaculation which means, you know, I'll never have kids. So that was something that I was really worried about going into the surgery.

It was going to ruin my sex life and, you know, I dealt with some of that before I even had my initial—I had my chemotherapy. You know, I banked, I did the sperm bank just in case. Before the surgery for some reason that wasn't a concern. So I had assurance from the doctor and he said that the surgeon did, you know, I don't know how many surgeries. It was over 40. And he said that the techniques are improved and that it wasn't as dangerous as it used to be. So I went for more surgery.

Daniel was concerned about the possibility of retrograde ejaculation and never having kids. He banked his sperm just in case he decided to have children in the future. Ultimately, Daniel was left sterile from his treatments. Unlike Nicholas, who feels upset due to his loss of fertility, Daniel is less concerned because he has always strongly considered adoption.

So for me the fertility issue was actually a bigger deal for my dad than it was for me. Before I was ever diagnosed with cancer I wanted to have kids but I didn't need it to be a part of me because I considered adoption before I had cancer and that's because I thought that it was—I think that it's kind of silly to bring more people into this world when we have so many other people that need, like so many children that need foster care or are orphans. I thought adoption would be a better prospect than actually having a kid. So it wasn't a big deal for me. I think it was a bigger deal for my dad just in terms of continuing our name.

Nicholas and Daniel were advised to bank sperm, and both did so. Both men have been left sterile from their treatments. Daniel wants to have children, but he does not feel that they need to be biological children to feel whole or complete. While the sperm banking technology may create some relief for Daniel because he knows he has that possibility in the future, he seems to be fairly content with or without his fertility.

However, many other men did not have the option to sperm bank and were left sterile without the option to use their own sperm in the future. Kevin, 39, was rushed to surgery and started chemotherapy immediately following his diagnosis. He was unable to find time to bank his sperm.

I didn't have time to sperm bank because everything had to be done so quick. You know most people get the option to a sperm bank and I didn't get that option. I had no time at all. And you know I know I'm not going to be able to have any kids and, you know, I'm 39 but, you know, I still have a couple more years and I was really interested in that, but now that that's not going to happen I just—it's hard to deal with some days, you know.

He continued:

Yeah, I didn't have—I mean they came in and it was about four hours after they removed my testicle and they said hey, you know, they told me I hope you're not busy for nine months, we'll start the chemo today. Well they came in later and said hey, look, at 10:30 at night, hey you know, we're not going to start chemo until tomorrow evening so if you can manage to get a hold of a sperm bank or manage to, I don't know how to put this but to be able to produce some sperm. And that just wasn't happening. I mean come on.

For Kevin, the idea of donating sperm immediately following the surgery that removed his

testicle and hours before he started chemotherapy seemed absurd. Ultimately, he was not able to donate and has been left sterile. Kevin was clear that the loss of his fertility is difficult to deal with. Like Nicholas, Kevin did not connect fertility with masculinity, but it is still the only side effect of his treatment that he claimed to still have difficulty handling.

While oncologists claimed that medical solutions fix fertility issues, some men, such as Kevin, did not have the option to bank sperm, and some men could not afford it. James, 28, was unable to afford the storage fees and hopes that he can maintain his own fertility. “I mean I might consider it again if I have to get chemo, but it’s not cheap to store sperm and I don’t have a lot of money.” He continued, “Yeah, and I don’t I just it’s not really something you ask for in a favor to borrow for so I don’t know. I guess I’ll cross that bridge if I have to.” He routinely mentioned that if sperm banking had been free, he would have participated. James was very clear that being fertile is important to him, and being able to have children is a goal for him and his wife. His hope of having children is very much a part of who he is, even though he did not necessarily tie fertility to his own masculine identity.

Other men bank their sperm as a precaution because having children is important to them.

Joshua, 29, stated:

After the surgery but before the chemo started, I had a very small window to connect with a fertility clinic so that I can—so they could freeze my—a couple samples of my sperm. *That was an important part for me too.* I mean chemotherapy they mentioned was going to wreck havoc on my normal cells and my body would probably shut down my reproductive system for a little bit. In some instances it comes back and in some instances it doesn’t, so if I ever wanted a possibility of having a biological child this would be a good option to consider right now, and I did.

I went to the fertility clinic and in one setting was able to donate, contribute, give, I don’t know, whatever they call it. And so I have my DNA frozen in some lab in Minnesota. I’m paying quarterly little fee—well not so little but a quarterly fee to make sure that I can still have the possibility and the option for a biological child.

Joshua wanted to keep the possibility open to have his own biological child. The very fact that so many men opted into banking their sperm shows that it was important to them. Most men hoped or assumed that they would still be potent after their surgery and/or chemotherapy. Men banked their sperm as a precaution, but they did not fully have to grasp their infertility until they were confronted with it—recall Nicholas, who was not expecting sterility and was left feeling surprised and isolated. Whether men lost their fertility or not, it was clear that having children was important to men and how they saw themselves.

Jeffrey, 43, was the only person I interviewed who banked his sperm and utilized IVF to conceive. Jeffrey's wife had a miscarriage with their first pregnancy right around the time of his diagnosis, and Jeffrey was concerned that he would not be able to have children.

Then that oncologist appointment I guess was in January, three months after we lost our baby. My oncologist said you know what, I want—here is my prescription for you now. I want you to go to a fertility specialist. He goes and what you guys have been through you need this. And so we went to a fertility specialist and we did a combination of keep doing the natural thing and doing artificial insemination stuff. And it was only the second time. The first time didn't take. The second time is what resulted in what I have now, so that was let's see, we got pregnant the second time. This was April and I was diagnosed in August and had my surgery in September.

So it wasn't that long after. You know and because we did artificial insemination and the natural way, but we knew exactly when she should be pregnant. We took the pregnancy test and we'd already been through it once and sure enough my wife walks out of the bathroom and had a plus again.

Jeffrey and his wife now have a three-year-old, but only when his wife was eight months pregnant did Jeffrey feel like he could breathe. Jeffrey was eventually advised that he no longer needed to store his sperm because his sperm counts were regular and the chemotherapy was out of his system. "In fact we ended up destroying the rest of the stuff at the fertility clinic because they said, you know, you have a kid and if you want to have another one you don't really need this stuff."

While Jeffrey's story played out well, it is unclear whether sperm banking is the solution that oncologists claim it is. While oncologists rarely even mentioned fertility as a concern for men, when the topic came up, oncologists presumed that sperm banking preemptively resolves any issues. However, some men who had banked sperm still have challenges facing sterility, and many men had not been able to sperm bank in the first place. It is clear that fertility is a concern given men's willingness to go into fertility clinics that focus almost exclusively on women and donate sperm just hours after being diagnosed with cancer. It is clear that all of their concerns are not resolved exclusively through sperm donation. Masculinity is so rarely connected to children that men's concerns about fertility are swept aside. I argue that even though men do not necessarily connect fertility to their own masculine identity, their ability to have biological children is still very important to them, and sperm banking may not actually resolve all of these concerns. Patients recount their doctors' nonchalance in telling them to bank sperm or that they might lose their fertility. As a consequence of the narrow definitions of masculinity, doctors assume that fertility is not an issue for men, and if it is an issue, that sperm banking resolves it.

SEXUAL FUNCTION

As shown in Chapter 3, masculinity is defined by men's ability to have sex. Doctors and survivors alike relate masculinity to sex but rarely discussed sexual function as an issue for women. However, men and women both face side effects that make sex difficult or impossible. Treatments for prostate cancer often leave men with erectile dysfunction. Treatments for breast and gynecological cancers can leave women with vaginal dryness and pain during intercourse, and in cases where radiation is involved, the vagina can close. Given that these treatments affect men's and women's ability to have sex, oncologists noted that they advise certain treatments. Because sex is seen as primarily a masculine concern, oncologists were quick to emphasize

fixing erectile dysfunction with Viagra and pumps. According to doctors and patients, Viagra is immediately prescribed after treatment. However, doctors rarely addressed sexual function as a concern for women, as femininity was defined in relationship to looks. Ultimately, women are left with fewer solutions and less support than their male counterparts.

Prostate Cancer Survivors and Viagra

Oncologists noted that prescribing Viagra or Cialis goes in conjunction with prostate cancer treatment. Many doctors said that they discuss prescription medications to ease concerns about sexual function for men. Dr. Cox, a male radiation oncologist, explained, “I think I feel like an obligation to discuss it with my male patients, because what I do to them directly affects their ability to have sex.” The radiation given to prostate cancer patients has the possibility to lead to impotence, and Dr. Cox noted that he must talk about sexuality with his patients because *what he does to them* affects their sex lives. When asked if he talks explicitly about sex with his patients Dr. Katz, a urological surgeon, said, “Oh, all the time. That’s part of my job in urology.” Similarly, Dr. McCarthy, a male urological medical oncologist, stated, “One thing, you absolutely have to be comfortable with discussing sex in an offhand way. If you can’t do that with old guys then, you know, it’s hopeless because that’s a big issue. You just have to, whether you’re male or female it doesn’t matter. You have got to be matter of fact about that aspect of things.” As a consequence, men with prostate cancer are almost always immediately prescribed Viagra in order to help with sexual function.³⁶ Dr. Simmons, a medical oncologist, said that most of her prostate cancer patients are on Viagra: “a lot of them are on Viagra or something.”

As shown in Chapter 3, men define masculinity with sexual function; however, as

³⁶ Viagra may not be prescribed if someone does not have insurance. Not having insurance may affect men’s ability to gain access to these pharmaceuticals and social class may play a role here. It is important to study how race and class intersect at pivotal junctures with gender like the treatment of gendered cancers. While I am unable to address class in this case, socioeconomic class is particularly important because it alters the types of treatment and the medical solutions available to patients.

Chapter 4 shows, it is the single male respondents who are more likely to have concerns about their *own* masculine identity. Below, I show that some men, especially those who are single, are more likely to utilize medical technology to preserve their sexual function in an attempt to bolster their masculine identity. However, other men, especially those in long-term relationships, do not feel that they need to rely on pharmaceuticals to maintain their masculine identity, even if they use them. Because so many men were clear that their own masculine identity was not connected to sexual function, these biomedical solutions are less important than doctors may have led us to believe.

For some men, the havoc that prostate cancer wreaked on their sexual function directly damaged their masculine identity. These men turn to drugs like Viagra to regain some potency and, thus, rebuild their masculine identity. For example, Thomas, our 75-year-old single prostate cancer patient who feels very emasculated because he does not have an active sex life, is clear that he is willing to take additional measures to resolve his erectile dysfunction. While originally reticent, Thomas now takes Viagra to manage the changes to his sexual function. He told me, “Well they’ve brought it [sexual function] up with me. They wanted me to take, what do you call it, Viagra, and I do now but I didn’t at first. They’ve asked me ‘how’s your sex life?’ Because that’s part of their treatment, they wanna know if they ruined my sex life because I can’t get a firm enough erection. They asked me that. They don’t anymore.” Thomas was clear that his doctors broached the subject of sexual function and actively prescribed Viagra. While he takes Viagra, Thomas also takes testosterone replacement to manage the side effects from his radiation.

Without getting into the weeds here, testosterone is the main male hormone and that depletes itself in your system as years go on and that had side effects of fatigue, irritability, weakness, loss of muscle mass and so forth and I’m getting testosterone replacement to feel better, enable me to go swimming and engage in

sports. But that's also a danger for a recurrence of prostate cancer. Going into the relationship between testosterone and prostate cancer is beyond me. So the urologists are treating me with testosterone guardedly, carefully and if my PSA starts to rise they will stop the testosterone.

It is—there's a widely held belief that prostate cancer development and growth is fueled by testosterone, I'm just gonna leave that there, but that is not always the case. But testosterone does help with male things like erections, that does help. So testosterone is my close friend and it works a little bit and—but it makes me feel good, it makes me able to work out in the gym, gives me more stamina, things like that.

While Thomas's doctors are cautiously prescribing the use of testosterone supplements, Thomas is adamant that he wants to continue taking the testosterone replacement because it helps with his energy levels and erectile issues. Both the Viagra and the testosterone replacement help Thomas feel like more of a man—he is better able to maintain an erection, work out, and feel less tired. In Chapter 4, I discussed how an active sex life was significant for Thomas, especially as a single man. It is clear that because of his concerns about his masculinity, which he defines through sex, he is willing to use these biomedical solutions. However, even though Thomas takes testosterone and Viagra, he still clearly struggles to feel secure about his potency and masculine identity. As a single man, Thomas actively connects sex with his own masculine identity and will take additional steps to keep his sexual function intact.

However, not all men who take medication for erectile issues spoke about concerns with their masculinity. Other men were clear that their masculine identity had not been impacted by their cancer experience, but they still use these prescriptions to manage the erectile dysfunction. For example, Roger, a 72-year old prostate cancer survivor, mentioned trying a few different prescriptions before he and his wife settled on Cialis. He was originally opposed to taking additional drugs, but his doctors kept suggesting it. “Dr. [name removed] suggested it to me. And even though he suggested it I was taking all these other supplements and things like that and I

had the boxes for six months and I went back to him—I was seeing him twice a year then. I said I haven't taken any Cialis yet." His urologist kept telling him to try the prescriptions. Roger decided to give them a try after he conferred with his son, who is also a urologist and said that there was no reason not to take the pills and that "we give this stuff out like candy." While he was clear he was not concerned about his sexual function prior, he stated, "Cialis is my best friend." Roger told me that he will not be concerned about his masculinity until his head stops turning at attractive women. Thus, Roger's sexual function and masculinity remain intact. Roger takes the Cialis because it was prescribed to him, but he asserts this his masculine identity would have been complete without it.

Similarly, Donald, 75, said, "I found that the common drugs used, Viagras, and Levitras and so forth helped so I was not terribly concerned about that [sexual function]." Donald worried more about having to wear a diaper in public and his ability to continue woodworking and maintain his motor skills. While he nonchalantly mentioned taking Viagra, Donald was clear that sex is not his primary concern and his masculinity is still unharmed. Therefore, Donald's sexual function and masculine identity remain intact.

Ron, 71 years old, also tried different solutions to help manage his potency issues, even though ultimately, he feels less concerned about sex. To start, Ron opted for nerve-sparing surgery to prevent some of the side effects.

Well if you have nerve sparing, it's easier to become potent again, you know to have an erection. If they take both the nerves out, it just gets—it's hard to do it—you pretty much have to use like a pump or something else. And if they take it on one side, then you know there's a possibility that the pills will work, as I say after two years, they were working with me. It wasn't like when I was young, but it was more pleasurable than using the pump.

Immediately following his surgery, Ron struggled to maintain an erection with the pills and started using a pump. After two years, he tried Viagra again with more success.

Yeah, I was on the pump and then they give—well I tried the Viagra and Levitra, I think even the other one. None of them worked about three months afterwards, I had no success at all. I said [to my doctor] I'd like to use the pump, you know when the other stuff didn't work as well. You know you've seen a man's magazine, and they've got this—you know they've got this bad reputation, but I mean it's— sometimes that's the only way you can—you can do it. So I went and did that, I used it and I had no problems using it, you know.

And after two years I said, well let me Viagra again, and it worked, not every time, you know sometimes the more you moved, you know when you had to move sometimes you know in—so it was a—but it just—it just felt, that—and one or two times I used a combination with the pump.

Using the pills just felt more natural because of the pump—you know you get—put the thing on and do other things, and you know just even though it wasn't as rigid as the pump, it just felt more natural. And even for my wife too because she said the pump, it felt cold. I don't know if it's because of the lubricant or what.

Ron was clear that having sex was not his, nor his wife-of-30-years', top priority. However, Ron still wanted to maintain a sexual relationship with his wife, so they experimented with pumps and pharmaceutical drugs until they found what worked best for them. Some men, like Ron, wanted to try additional solutions to maintain an active sex life with their partners, even if their masculine identity was intact.

Raymond, 71, is opposed to the idea of using a pump and figures if his ability to maintain an erection did not come back on its own, he and his wife would be fine.

I don't like the idea of pumps and all that crap. I mean it just is what it is, you know. If that's the blow I've been dealt I'm going to deal with it. And you know what, after you get to be a certain age you don't have sex every day, I'll tell you. I don't know what a lot of other people do but I know they don't.

He continued, "I mean well I'm more interested in companionship, you know, and love and family, you know, that's far more important than the fact that I may lose my sex drive." While Raymond said that he might be willing to try Viagra, the idea of using a pump was out of the question. For Raymond, an active sex life is not necessary to maintain a masculine identity; therefore, he does see much use in the biomedical technologies available to him. Like Ron and

Donald, Raymond does not connect his own masculine identity with sexual function. Therefore, fixing his erectile issues is not going to affect how he feels as a man.

Terry, 63, is open to the idea of using pumps and Viagra, but he recognizes that his sexual function is his and his wife's last priority. "Like on our list it [sex] is the fourth. And like I'm good with it. I'll try whatever... I'll just deal with it then." Like Raymond, Terry explained that he would be fine if he is not able to maintain the same sex life that they had prior.

Patients mentioned the use of Viagra in such a matter-of-fact way that it became clear that the drug is a standard piece of any discussion about prostate cancer treatment. Doctors preemptively prescribe Viagra to all of their patients, regardless of whether these men are actually concerned about their sexual function. Patients were open to the idea of trying prescriptions in order to maintain function, even if potency was not a primary concern. As shown in Chapters 3 and 4, most of the prostate cancer survivors I spoke with claimed to not have concerns about their masculine identity due solely to their loss of sexual function. As I argue in Chapter 5, their own sense of masculine identity may ultimately be more affected by the loss of control that cancer posed. However, their doctors only sought out conversations with them about sexual function and pharmaceuticals. Because doctors and patients conflate masculinity with sexual function, oncologists prescribe Viagra and other drugs to help men cope, yet they ignore broader understandings of masculinity. Thus, doctors do not address these men's feelings of helplessness and vulnerability, resulting in a crisis of masculinity among many prostate cancer patients despite the prevalence of Viagra.

Women's Sexual Function

Oncologists rarely acknowledged that sexual function is an issue for women because oncologists conflate femininity with appearance and sexual function with masculinity. Therefore,

advice for women who had difficulty with their sexual function was rare. When I asked Dr. Yarborough, a radiation oncologist, what advice she had for women with issues surrounding sexual function specifically, she said:

We try medications. Like if they're a gynecologic cancer patient, I have tried hormone therapy, estrogen therapy, testosterone therapy, these devices that increase the blood supply to their pelvis. I mean I've tried a million things to try to help them with that (sexual function).

Additionally, when I asked Dr. Richardson, a radiation oncologist, to what extent she talked to her patients about their concerns for sexual function and femininity, she said:

You know, I do talk about it but I am not a psychologist, so I can make concrete recommendations like using vaginal lubricants, but I'm not the sort of person who is going to say oh, well fix a nice romantic dinner. Most of them actually get over it as they get away from treatment, start to feel more like their old selves, they find ways of dealing with it.

Dr. Richardson made it clear that sexual function is not really her strong suit, even though her treatment radically alters women's ability to have sex. Oncologists rarely mentioned women having issues with sexual function, but when they did, they mentioned that they prescribe lubricants and other medications to fix these issues. The oncologists downplayed this particular issue, emphasizing that women eventually find ways to deal with it.

However, a number of the gynecological cancer survivors I spoke with were left with side effects that greatly impacted their ability to have sex. Many of them felt like they had not been given answers. Just as men who lost fertility did not connect this loss to their masculinity, the women who lost their ability to have sex did not connect this to their femininity. However, my analysis will show that the damage to women's sexual function is still important and may be going unnoticed because we assume that only men have concerns about sexual function.

For example, Barbara explained the uncomfortable side effects she experienced after her hysterectomy:

Well, physically a typical 74-year-old woman would be having some sort of vaginal atrophy and dryness and that sort of thing, and I think it's worse because of the experience that we've been through. So intercourse would be painful now. And obviously we can't take hormones because we've had cancer, gynecological cancer, so there isn't any hormone replacement therapy or anything like that. So you're just sort of stuck with that. So there's that.

And then there's a diminished libido although every once in a while you know you feel attracted to somebody and so that's when I say I think it's physical, I don't think of it—it's—I think it's function, the function of the body.

When we talked about whether Barbara had asked her doctors for solutions to the pain associated with sex, she said, "I've talked to my general practitioner about that, and she's recommended lubricants and that sort of thing. But they don't really help." Barbara did not know what other solutions there may be. She decided she would pose this question to the women of her support group because many of them talked about remaining intimate with their husbands. Barbara even asked me if I had heard of other solutions from doctors, and I told her that lubricants were the only things that oncologists mentioned in my interviews. Recall Barbara's concerns about intimacy from Chapter 4—she considered getting massages to feel more affection in her life. While she is dating a new man, they are unable to have penetrative sex. "I am dating a very sensual wonderful man, and we've had something that approximates sex, but it isn't full on penetration type." Barbara's side effects have left her feeling disconnected because she is unable to have the sex life that she wishes.

Janet, 55, also experiences a lot of vaginal dryness and was prescribed a cream that only helps a little. When outlining her long-term side effects, she said:

I get a few more hot flashes and you get the vaginal dryness and you know. I didn't really notice that so much until now, so perhaps that's a new change is that there's differences in the tissue that I talked to my surgeon about and he gave me a cream, but actually the cream, it comes with all these warnings about uterine cancer and blah, blah, blah. I don't have all those organs anymore but I use it sparingly because it's like I have enough risk of cancer. It helps a little.

Barbara and Janet both experienced dryness and pain with intercourse and asked their doctors for solutions. After confronting their doctors about these side effects, they were given lubricants or creams to deal with the symptoms. However, both Barbara and Janet were clear that the solutions provided to them were not very helpful.

Women who underwent radiation to these areas also faced sexual side effects. Rebecca, 55, was diagnosed with uterine cancer and received radiation to the entire pubic area. When Rebecca explained the side effects of the radiation, she noted that the body builds up scar tissue that ultimately tries to close the vagina. As a consequence, Rebecca has to use a dilator to keep the vagina from closing.

The other permanent side effect is because of the internal beam the body scarring in the vaginal area and the vaginal cuff, the body wants to produce fibers and close down that area completely. So those of us that have had the internal high dose use what's called a dilator. It is a silicone or plastic instrument that must be used for the rest of our lives. Otherwise it can close completely and if there is any need for examining for a future cancers or anything, the vagina can close off. It's quite painful in the beginning. I think after now I'm at the 10-month mark, after treatment. I think I've created more of a rhythm that I can live with.

Even though she is ten months out from treatment, Rebecca still experiences a great deal of pain, and she cannot be intimate with her boyfriend. "And my relationship with my boyfriend is still on hold because I don't have comfort in my body functions yet." None of her doctors fully explained the extent of the changes to her body or sexual function.

Well they gave me a piece of paper with two dilators, two different sizes, and some written instructions for the rest of my life. That was so painful because those were the very hard, plastic that had been cut from some type of a design, so I explained that to my nurse practitioner when I went in for my next exam, and she recommended a silicone version which I then have ordered and that's at least something that I can tolerate.

When I asked Rebecca if she was able to talk to her radiation oncologist about these concerns, she said:

Not the oncologist because he turned bright red when I spoke to him about that, and he knows my OB/GYN and my OB/GYN was calling me at home. He knew what I was encountering before I encountered it. And the oncologist is not comfortable working on that area of my post care treatment at all. So I have visited my OB/GYN twice specifically for what do I do, how do I cope with this new ongoing lifelong body change?

Given that these side effects were a consequence of her treatment, it is surprising that her oncologist was embarrassed to speak with her about these side effects. Urologists were clear that talking to men about sex was a necessity because sexual dysfunction results from their treatment. However, it seems that doctors found discussing changes to women's sexual function less comfortable. When I asked Rebecca how she felt about the changes to her body and she said, "It's disturbing." But she went on to say, "I'd rather have my life than an intimate sexual life and give in to the cancer, so this course of treatment is my choice and I'm not regretting completing it and following through and I will live with the consequences whatever they are." While Rebecca does not connect these issues with femininity, it is clear that her sexual function has been impacted. Even though sexual function is not connected with women socially, it would be remiss to assume that Rebecca is not affected by these side effects. While she may not articulate it as such, I argue that Rebecca's sexuality and her life have been greatly affected.

Pamela, 47, also had severe side effects from the radiation near her pubic area and still experiences these side effects five years later. When she explained the effects of the radiation, she said:

Radiation over time was painful, very painful. It basically radiates from the inside out, and by the time it got to the outside you ended up being red like a sunburn all the way to black skin like you were burnt like a marshmallow. Then skin would fall off, and then you get rejuvenized skin again... But physically, it was very painful physically and probably because of where it was at. When I got radiation, I got it in the front vaginal area, and I also got it in the back. Anything basically between your legs got hit and so there was a lot of damage that was done; partially dealing with the side effects from that today. But I would say the pain of the final days of radiation, I mean you can't walk well, your skins falling off; you

can't wear clothes that are uncomfortable.

The pain doesn't go away because you're still going to the restroom. The urine burns the skin. In between all that you have diarrhea and everything burns. There's no way of getting away from the pain unless you were put into a coma, which I didn't want nor was it a possibility; it was just to deal with it kind of thing.

Pamela described her side effects and experience of radiation vividly. She was clear that even five years out from radiation, she still has side effects. She continued,

Yeah, like, for example, my skin still has a tendency to rip. It doesn't ever really heal. Radiation basically shrinks the area and so vaginally I haven't been able to recover in that way. I've had the skin actually peels itself so it actually grew together and closed my vagina. Then I had to have surgery to open it back up. I've had a domino effect of just things going wrong health wise... And trying to still deal with the day to day of urinating without burning the skin, wiping yourself without ripping your skin...

Like Rebecca, Pamela experienced a number of particularly unpleasant side effects due to the radiation and was offered very little support on how to handle these changes. Pamela had not received information on a dilator, and her vagina did indeed shut. She had an additional surgery to re-open the area. Even after five years, the skin in that area is still incredibly sensitive and tears. Towards the end of our interview, Pamela said,

Oh I think I've recouped from back then. I'm good. I don't feel a loss from having cancer, I feel a gain. I feel a gain of medical awareness, my relationship you know gain of better communication all the way around not just with my husband and my family and my kids all the way around. Life in general a better standing better on my feet I mean obviously I needed to become a stronger person than what I was and that's I think that cancer comes for a lot of reasons, and all of those were mine.

We ended our interview with her saying, "I'm comfortable with who I am, and I'm comfortable with what I had and what I went through, and I know the drill." While Pamela was adamant that she is "good" and that her femininity is intact, it is clear that her sexual function is still greatly affected.

Because oncologists conflate femininity with appearance, they do not recognize other issues—such as sexual function—as being problematic for women. Therefore, oncologists are less likely to discuss biomedical solutions to women’s difficulty with sexual function. However, women who experience these treatments do have problems with sexual function.³⁷ While patients and oncologists do not connect women’s sexual function with their femininity, it would be careless to assume that women’s sex lives are not significant and important in who they are as women. Thus, by focusing on femininity as appearance, doctors miss a crucial point where they could use biomedical technology to help their patients address a gendered issue. By ignoring women’s sexual function and thus not discussing the related biomedical solutions with their patients, doctors also inadvertently worsened some women’s recoveries. Thus, doctors’ understandings of gender combine with biomedical technologies to have real consequences for their patients’ recoveries and own gender identities.

Some tools are automatically offered to some patients based on oncologists’ cultural assumptions about masculinity and femininity. Seventy-year-old prostate cancer patients, such as Roger, whose doctor insisted for months that he take Cialis, were proactively prescribed medication to resolve erectile dysfunction because sex is seen as a primarily masculine concern. However, young women, such as Pamela who was in her early 40s, were given little instruction or support about the sexual side effects that they may face. These examples stand in stark contrast and show the social implications of doctors’ assumptions about gender.

CONCLUSION

Given oncologists’ cultural understandings of masculinity and femininity, doctors privilege specific biotechnologies as solutions for these concerns. These narrow definitions of

³⁷ Rasmusson and Thome (2008) also find that women want their doctors and nurses to proactively provide information about the changes to their sexual function and feel that they are not given adequate information.

masculinity and femininity privilege certain concerns and ignore others. Doctors emphasize that sex appeal attacks women's femininity and prescribe reconstructive surgery to fix these issues. Moreover, doctors emphasize Viagra as the solution to men's concerns, defining sex as primarily masculine. Oncologists' belief that masculinity is about sex and femininity is about physical appearance leaves little space for considerations of fertility for women and men. Additionally, doctors' belief that biomedical technologies solve men's and women's issues is upheld by their confidence that fertility is no longer an issue for men and women because of sperm banking and egg harvesting . Ultimately, this leaves women with fertility issues and, more surprisingly, sterile men feeling hurt and damaged.

Even more striking is the stark contrast between conversations about men's and women's sexual function. Because masculinity is seen as rooted in a healthy sex drive and sex life, Viagra and discussions surrounding impotence and erectile dysfunction were prominent in my interviews with oncologists. Oncologists were quick to note that Viagra was given to anyone who was diagnosed with prostate cancer (and older men more generally). However, the technologies available to women facing sexual dysfunction were limited, and women recounted being given very little information and feeling uncomfortable talking to their doctors about these changes. Because oncologists connect sexual function to masculinity, they are prepared to address these concerns, even if men do not feel emasculated. As a consequence, the ability to have sex is not seen as a concern for women, and these technologies and conversations are not made readily available.

CHAPTER 7: CONCLUSION

In this study of cancer survivors who have been diagnosed with breast cancer, gynecological cancers, testicular cancer, and prostate cancer and the doctors who treat these diseases, I analyze the socially constructed nature of gender and the body. The involuntary disruption to the gendered body that results as a consequence of the cancer experience presents a unique opportunity to understand how men and women recognize their own gender identity in relationship to their body. This dissertation is particularly enlightening because it compares the experiences of men *and* women who face changes to their appearance *and* sexual function.

If I had only studied women, this dissertation would have lost a majority of its impact because definitions of masculinity and femininity are defined against one another. I would not have been able to analyze the different ways that men and women discuss the importance of sex and sex appeal and the divergent affects on their identities. While I may have been able to show that women felt more empowered than the literature suggests, this finding would be far less compelling if I were not able to show the relative powerlessness for men. Gender is a relational system where men understand who they are and how they should behave in opposition to women. Studying both men and women allows for a more clear and meaningful argument about the socially constructed nature of gender by looking at the conflicting understandings about the importance of resolving the changes to men's and women's bodies.

Chapter 3 outlines the narrow ways in which men and women, both survivors and doctors, understand masculinity and femininity. I show how masculinity is socially defined in relationship to sexual function, focusing on the prominence of sex and erections to being understood as a man. Because masculinity is conflated with sex, the ways that cancer could challenge men's masculinity in other ways are ignored by oncologists and survivors. Therefore,

the ways that cancer might affect men's independence, ability to work, or fertility are rarely connected to masculinity. While sexual function is a real concern for many men, I find that most men do not connect their own gender identity to their ability to have sex.

Doctors and patients perceive physical appearance as the foundation for femininity. Thus, doctors and survivors also overlook broader understandings of what it means to be a woman. Cancer challenges women's ability to bear and birth children, their ability to engage in penetrative sex, and the time and energy they can devote to their children and families. When asked about femininity, women reveal their assumption that being a woman is connected to looking appropriately female, yet many argue that their own identity is not directly tied to their appearance.

Many of these survivors point to their spouse as the sole reason why their gender identity has not been impacted by their loss of potency or changes to their bodies. In chapter 4, I outline the importance of marriage as an institution in allowing men and women the space to disconnect how they see themselves from the broader cultural definitions of what it means to be a man or a woman. Married people feel a sense of security and are able to challenge the definitions of masculinity and femininity. Single people are left with fears that new partners will not be interested in a relationship given these changes to their bodies. This lack of security leads single people to solidify their belief that who they are is about the appearance or function of their body. Therefore, for this group of people who have had involuntary changes to their bodies, marriage becomes a key institution in dismantling patriarchal views of men and women. This goes against what the literature has shown previously, which suggests that marriage and the home are the foundation of gender-essential beliefs that sustain gender inequality (Ridgeway 2011). The

security that men and women feel in marriage provides a space for them to recognize that they are more than their looks and ability to maintain an erection.

This security allows women to move beyond the belief that their gender identity is tied to their appearance. Therefore, rather than feeling damaged or a loss of a sense of self, women feel empowered. As I explored in Chapter 5, going through the cancer experience provides a unique opportunity for women to recognize their strength. This is surprising given how drastically breast cancer and gynecological cancers affect women's bodies. Scholars have argued that undergoing cancer treatment creates a loss of identity, particularly for breast cancer patients because of concerns about their self-image (Ericksen 2008; Ferguson 2000; Klawiter 2004; Lorde 1980; Potts 2000; Rasmussen et al. 2010; Rosenbaum and Roos 2000). Most of the scholarly literature on the experience of women with cancer focuses on how the damage to women's bodies alters their sense of self. However, I find that most of my respondents do not feel as damaged as they expected. The women I interviewed feel secure with their feminine identity, regardless of what shape their bodies take.

However, for men, cancer challenges their masculinity in unexpected ways. Because men disconnect their own gender identity from sex, they are left to maintain their masculinity through strength, control, and rationality. Cancer challenges these traits and leaves men feeling powerless and vulnerable. Because sexual function is connected to masculinity, oncologists proactively address men's concerns about sex by prescribing pharmaceutical solutions to fix erectile dysfunction. While men make use of these solutions for a variety of reasons, there is little support for men to cope with other emasculating side effects that they confront with a cancer diagnosis. This leaves men, particularly older middle-class men, feeling out of control and vulnerable because as men they have been bestowed a certain degree of power and authority.

Additionally, because childbirth and childrearing is understood as primarily a feminine issue, men who face fertility problems are also left without adequate support. The narrow conception of masculine concerns may have negative consequences for many men.

Additionally, sex is *not* culturally connected to femininity, even though women face devastating changes to their sexual function. As a consequence, women are left with few solutions and little guidance from their doctors. Men facing issues with potency have a variety of technologies at their disposal: pumps, Viagra, and Cialis. Doctors go to great lengths to change or postpone treatments, spare nerves, and counsel men on these changes to their sexual abilities. Women, on the other hand routinely face vaginal dryness and pain during intercourse and in extreme situations closure of the vaginal canal and they are generally only prescribed a cream—if they're lucky—with little instruction or support. I do not want to make light of men's situation, as impotence does in fact affect their quality of life. However, I argue that if men faced similar side effects to women, there would be widespread social concern about these problems, more treatment options available, and more emphasis on correcting these side effects. Studying both women's and men's access to biomedical technology to fix sexual dysfunction highlights the importance of studying both men and women. This comparison brings additional insight into how understandings of gender shape cancer treatment and patients' experiences.

As cancer survivors disconnect their own gender identity from the appearance and sexual function of their bodies, gender is undone in a variety of ways. Just as gender is “done” through interaction (West and Zimmerman 1987), gender can also be deconstructed and changed as men and women destabilize the taken-for-granted characteristics (Connell 2010; Deutsch 2007; Risman 2009). First, cancer patients challenge the socially constructed belief that our gender identities are dictated by our sexed bodies. As married men and women shift their gender

identities away from their sexual function and appearance, they undo normative expectations of what it means to be a man or a woman. Feeling the love and support of a committed partner allows men and women to challenge gender expectations. Contrary to the gender literature, marriage becomes a site for undoing patriarchal and unequal structures and beliefs.

Second, gender is undone as men and women become comfortable with the changes to their physical bodies. When testicular cancer patients choose not to have prosthetics, when breast cancer patients with mastectomies opt out of reconstructive surgery, and when ovarian cancer patients refuse to hide their scars, these individuals challenge widespread assumptions about what men and women should look like. By opting out of additional surgeries, cancer patients challenge gender norms and the biomedical emphasis on “fixing” flawed bodies.

Third, gender is also undone as men become more emotional and vulnerable and women take on narratives of strength, empowerment, and independence. The changes to men’s masculine identity as they accept more empathetic and emotive practices may allow men to engage in different types of masculinity above and beyond practices that demonstrate dominance and subordinate women. Similarly, as women’s feminine identities become connected to their strength, and as women continue to advocate for and prioritize themselves, these cancer survivors change the perception that women are inherently weak and vulnerable to subordination. First and foremost, these women embody strength themselves. Two of my respondents left their husbands after their cancer experience, many of them discuss standing up for themselves at work and in the home, and a majority mentioned that other people now recognized their strength, including their children. These women challenge cultural expectations on a daily basis by advocating for themselves. Additionally, as these narratives of strength become more visible and grow in number, they have the potential to influence younger

generations of women to feel empowered, regardless of the shape of their body. Younger generations of women are already beginning to challenge normative ideas of feminine bodies on social media with hashtags like #selflove, #stopbodyshaming, #strongisthenewskinny, #bodypositive.

It is also important to discuss how this dissertation highlights human beings' resilience when confronted with illness and adversity. While this is not the goal of this dissertation, I find it necessary to note given that so many men and women face cancer diagnoses on a daily basis and are then expected to put the rest of their lives on hold while they endure months to years of treatments. Nearly 5,000 people in the United States are diagnosed with cancer each day. I applaud the resilience of all cancer survivors, their families, their friends, and their extended support networks. While I compare the side effects of men's and women's cancers and treatments, I do not take lightly that cancer diagnoses and treatments are severe, devastating, and terrifying. I was continually reminded of the strength of the human spirit as most of my respondents talked at length about the positive sides of their experience, their gratitude for the changes that they had made as a consequence, and the fortune that they felt.

SIGNIFICANCE

This dissertation also makes suggestions for practical changes within the medical field. My results are likely to give medical experts and patients a greater understanding of the social experience for cancer patients. Given the large numbers of men and women who are diagnosed with a gender-specific cancer each year, having a better understanding of the cancer experience for both women and men may help improve the types of support that cancer patients receive. I encourage the medical community to move beyond their cultural definitions of masculinity and femininity so that they are open to patient concerns that do not fit their assumptions. I hope that

this provides an opportunity for additional research and support for women facing vaginal side effects and men and women facing sterility. Doctors should be more clear about the potential risks involved in undergoing reconstructive surgery, in the same ways that they outline the risks of prosthetic implants for men with testicular cancer. Even women who asked their doctors why they would not want reconstruction were told that there was not any reason to opt out.

Additionally, I encourage doctors to be aware of the unintended social consequences of prescribing reconstructive surgery and Viagra in reproducing normative gendered bodies. Doctors should be more understanding of women who opt out of reconstruction and men who feel fulfilled without firm erections. Rather than seeing these patients as challenging the medical establishment, these individuals should be applauded for their resistance to culturally oppressive beliefs. I encourage medical professionals to be more open about discussions surrounding the social construction of gender, deemphasizing the necessity to fix the body and emphasizing the opportunity to change one's identity.

Further, I hope that this dissertation can help prepare individuals diagnosed with gender cancers. This study provides information about the symptoms that individuals may face and an opportunity to other cancer survivors' stories. I would also advise men and women who are diagnosed with gendered cancers to problematize and challenge normative ideas about what gender really means to them and their identity. More practically, I would advise women to be more open with their oncologists about their sexual needs and to push their doctors to give them pre-emptive treatments to resolve these issues. I would also advise men to be more clear with their doctors about their fears and concerns beyond those of sexual function so that oncologists have a better understanding of the effects of their treatments. Additionally, I hope that men and women are able to find ways to gain security with their own gender identity outside of marriage.

Gender is more than just a variable used by demographers and epidemiologists to analyze differential health outcomes and treatments. Gender is a social structure that is embedded within institutions, such as medicine. Medical care is both shaped by ideas about gender and reproduces those beliefs through the bodies of patients. Medicine has historically been and is still currently an important institution in creating and maintaining social beliefs about gender, the body, and what is considered normal, healthy, and well. Understanding oncologists' assumptions about masculinity and femininity and their subsequent biomedical advice allows us to better understand how medical professionals may be reproducing beliefs about gender and the body. As doctors suggest that breast cancer patients face additional risks to undergo reconstructive surgery but discourage testicular cancer patients from a more minor surgery, oncologists reproduce the idea that having a physically appealing body is a more significant symbolic asset³⁸ for women than are the testicles for men.

These doctors may be unconsciously reproducing normative ideas about what it means to be a man or a woman. This has real consequences in reproducing essential beliefs about gender as something that is inherent within us and connected to our physical bodies. As I have shown, men and women with cancer challenge these scripts on a daily basis; however, these beliefs are also reproduced as doctors prescribe treatments to “fix” abnormal bodies. The reproduction of gender essential beliefs leads to a number of gender inequalities; namely the continued domination of women by men, oppression of lesbian, gay, and bisexual identities, and suppression of trans-identities and trans-bodies.

Additionally, while sociologists critique the institution of marriage for its role in maintaining and reproducing patriarchal structures (Ridgeway 2011), it is important to

³⁸ Schrock and Schwalbe (2009) assert that (fe)maleness and (wo)manhood are connected to the body as a symbolic asset.

understand how these committed relationships may in fact allow women and men an opportunity to change their gender identities in less patriarchal and culturally expected ways. While cohabitation has increased and marriage rates are declining, a large majority of Americans still get married. In 2009, 55% of people over the age of 15 had been married at least once (census.gov). And even those who have not been married still hope to. Most Americans (61%) who have never been married say they would like to be married some day, while only 12% say they do not want to marry (pewsocialtrends.org). The endurance of marriage as a central institution to American life suggests that it will continue to play a role in the deconstruction of gender for survivors of gendered cancer, providing a space where women become empowered and men are allowed to be vulnerable.

FUTURE RESEARCH

I argue that the disruption to the gendered body from cancer treatments results in a shift in gender identity for men and women. Women's identities shift away from their appearance and they become empowered. However, men lose control. While their gender identity is not affected by the changes to their sex lives, their identities shift and men become more vulnerable. I argue that this is a consequence of the changes to men's and women's bodies from their gendered cancers. This involuntary disruption rarely happens outside of cancer diagnosis. While men experience erectile dysfunction, and men and women face sterility for a variety of reasons, I would argue that the changes to men's and women's identities are compacted with a cancer diagnosis. Cancer is a significant site because of the gravity of the word cancer and the fear that it imposes. However, I think future research could look into how unexpected changes to gendered bodies outside of cancer affect men's and women's identities differently.

I would also encourage future researchers to look at how men's and women's identities change over time. I interviewed survivors at a variety of stages, some with recurrent cancer, some recently in remission, and some who had been in remission for nearly ten years. There were no noteworthy differences between these groups. However, time may play a role worth analyzing.

Lastly, with increasing biomedical technologies created to solve gender issues and an understanding of how medicine contributes to reproducing gender essentialist beliefs, I encourage medical educators to teach future doctors how they can help challenge these cultural discourses surrounding gender. Medical professionals should be taught about the social construction of gender and doctors' role in generating these ideas about normal gendered bodies. Additional research should look into the success of medical education in teaching how gender as a social structure is embedded into all institutions, including seemingly objective institutions like medicine and science.

APPENDIX A: INTERVIEW GUIDE FOR ONCOLOGISTS

Could you explain and describe what you do?

Why did you go into oncology?

How long have you been practicing medicine?

How did you get where you are now? Could you explain your career trajectory?

In what capacity and to what extent do you work with cancer patients?

How do you generally break the news to a new patient that they have cancer?

How do people usually respond when you tell them that they have cancer?

Have you always [informed, broke the news, or consulted] patients in this way or has your approach changed over time?

How so?

If so, what motivated you to change your approach?

Can you describe a significant moment with a patient that has a lasting effect on you today?

What strategies do you employ to manage the emotional aspects of your job?

What is the hardest part of your job?

Is there general advice that you give to your cancer patients?

If so, what do you tell them?

Did you develop this advice on your own?

If so, how did you develop it?

If needed, have other people helped you develop this advice?

If so, were they other doctors?

If not, who were they?

What were these discussions like?

What is the most important aspect of the doctor-patient interaction on the human side?

In what capacity and to what extent do you work with residents, medical students, and fellows?

What do you explicitly teach them about the human side of doctor-patient interaction?

How much of this training is implicit?

What is your favorite part of your job?

If interviewing a doctor that works predominantly with female patients (gynecological cancers in particular)

What type of gynecological cancer do you specialize in?

What are the various treatments for _____ (uterine, ovarian) cancer?

What are the side effects for these treatments?

What are the side effects, if any, for a hysterectomy?

How do women generally react to hearing the news about these side effects?

Do you discuss these side effects with the patients? To what extent do you give advice about their concerns?

If you don't discuss these issues, who do you refer your patients to?

What types of brochures or self-help books do you suggest for your patients when they have concerns about having a hysterectomy?

Do women address a concern about a loss of 'self' with the effects of the surgery?

How so?

What advice would you give a young female patient in her 20s or 30s about having a hysterectomy?

What advice would you give an older female patient (over 50) about the hysterectomy?

What advice would you give to a woman having a hard time with a hysterectomy in terms of her femininity?

What characteristics do you take into account when giving patients advice on how to handle their surgeries?

How does _____ (say they say age, marital status, etc.) factor into these decisions?

How do you think the patients' gender affects the loss of an important body part and their response to it?

What are the biological affects of radiation or a hysterectomy in relation to one's gender?

What characteristics do you take into account when deciding how you should to your patients (either when breaking the news to them about their diagnosis or treatment options)?

Can you describe the advice that you would give a 30-year-old expressing concern about infertility?

I've heard in other interviews that some patients after a hysterectomy talk about feeling like less of a woman, what would you say to a patient who expressed concerns of feeling like they were no longer women?

As a woman (man), how does your approach or perspective to _____ cancer differ from your male (or female) colleagues?

If interviewing a doctor that works predominantly with male patients (prostate cancer in particular)

What are the various treatments for prostate cancer?

What are the side effects for these treatments?

How do these treatments affect the function of the penis?

How do men typically react to hearing the news about these side effects?

Do patients' ever express concerns about how these side effects are going to affect them as men?
How so?

What advice would you give a young male patient in his 20s or 30s about the threat of impotency?

Do you discuss these side effects with the patients? To what extent do you give advice about their concerns?

If you don't discuss these issues, who do you refer your patients to?

What types of brochures or self-help books do you suggest for your patients when they have concerns about the loss of function of their penis?

What advice would you give an older male patient about the side effects of surgery on his prostate?

What advice would you give to a man having a hard time with surgery on his prostate in terms of his masculinity?

What characteristics do you take into account when giving patients advice on how to handle their surgeries?

How does _____ (say they say age, marital status, etc.) factor into these decisions?

How do you think the patients' gender affects the loss of an important body part and their response to it?

As a woman (man), how does your approach or perspective to prostate cancer differ from your male (or female) colleagues?

If interviewing a doctor that works predominantly with female patients (breast cancer in particular)

What are the various treatments for breast cancer?

What are the side effects for these treatments?

What are the side effects, if any, for a mastectomy?

How do women generally react to hearing the news about these side effects?

Do women address a concern about a loss of 'self' with the loss of a breast?

How so?

Are women generally more concerned about the loss of a body part as they are losing a part of themselves or specifically the breast because of its gendered significance?

What advice would you give a young female patient in her 20s or 30s about the loss of a breast?

Do you discuss these side effects with the patients? To what extent do you give advice about their concerns?

If you don't discuss these issues, who do you refer your patients to?

What types of brochures or self-help books do you suggest for your patients when they have concerns about the loss of their breast(s)?

What advice would you give an older female patient about the loss of a breast?

What advice would you give to a woman having a hard time with a mastectomy in terms of her femininity?

What characteristics do you take into account when giving patients advice on how to handle their surgeries?

How does _____ (say they say age, marital status, etc.) factor into these decisions?

How do you think the gender of the patient affects the loss of an important body part?

As a woman (man), how does your approach or perspective to _____ cancer differ from your male (or female) colleagues?

APPENDIX B: INTERVIEW GUIDE FOR PATIENTS

I appreciate your willingness to help me with my project. Before I ask any questions, do you have any questions for me?

1. Can you tell me about yourself and your personal background?
 1. Do you have any family? *Only ask if this hasn't been touched on.*
 2. Were/are you employed? *Only ask if this hasn't been touched on.*
2. Can you tell me about when your illness began?
3. Can you describe the experience of learning your diagnosis?
4. Can you describe to me what you recall thinking at the time of initial diagnosis? ** ³⁹
5. Can you tell me about the experience of deciding to start treatment and the decision-making process about what types of treatment you would receive?
 1. Can you tell me about how you decided on your course of treatment?
 2. Did your family members participate in the decision to start treatment? Did you consult anyone else when you decided to start treatment?
 3. Did you consult another doctor in order to get a second opinion? Can you tell me about this process?
6. What were you most concerned about when deciding on a course of treatment?
7. Can you describe your experience undergoing these treatments? *I will break this down to ask specifically about their experience with each treatment.*
 - How did you feel after surgery?
8. What side effects did you experience with _____ treatment?
9. What is different about your body since your diagnosis? **
10. Can you discuss how you felt about the changes to your body undergoing _____ treatment?
11. Do you think you have received/are receiving adequate information from health care professionals? **
12. Do you feel comfortable discussing the changes to your body with your doctor?
13. Can you tell me a little bit about your support network while you were undergoing treatment?
14. Have you attended/did you attend any support groups?

³⁹ ** Adapted from Mathieson and Stam (1995)'s interview guide.

15. What do you think about the care that you have received? What services are most important to you?
 16. What has been the most difficult part of this experience?
 17. Do you consider yourself to be religious?
 1. How has this shaped your experiences?
 18. How has your diagnosis and treatment affected your personal life?
 19. How, if at all, did these treatments affect your work life?
 20. How, if at all, have these experiences affected relationships with your family?
 21. How, if at all, have these experiences affected your sense of self?
 22. What is different about yourself since your diagnosis? In other words, do you see yourself differently now than you did before your diagnosis?*
 23. Do you think people see you differently? How so?
 24. What moments do you notice the differences between yourself before and after treatment? Can you describe these?
 25. How has cancer and cancer treatment shaped your goals for the future?

What would you say is your highest priority now? Before your diagnosis?
 26. Some people have said that they felt that this experience was ‘enlightening’. Have you felt this? If so, what has been the most enlightening experience?
 27. What have you learned about yourself throughout this process?
 28. What lessons have you learned?
 29. What would you do differently?
-

30. Have these experiences changed how you view yourself as a woman?

.....

 - How has this experience changed your perception of your femininity?
 - Can you describe the first time that you looked in the mirror after surgery?
 - Can you describe the first time that you showed your husband/significant other your body after surgery??
 - What was it like for you when you first bought a prosthetic? Can you describe this experience?

- Some women addressed concerns about not feeling sexually attractive after surgery, did/do you ever feel this way? Can you describe this? Why do you think you felt this way?
 - Do you think you would feel differently if you were/were not married?
-

29. Have these experiences changed your view of yourself as a man?

-
- Do you think this experience has changed your perception of your masculinity? If so, how?
 - During a few discussions with oncologists, they noted that most men's biggest concern during treatment was their sexual function? Would you say that this is accurate?
 - Is this something that others bring up in support groups? Have you discussed these changes with anyone?
 - Do you think you would feel differently if you were/were not married?

31. Do you identify as a 'survivor'?

32. What does the word 'cancer' mean to you?

Ask potentially for snowball sampling...

1. Have you ever had a family member or friend that has been diagnosed with cancer?

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