THE UNIVERSITY OF CHICAGO

EMBODYING GENDER THROUGH CANCER:

MEDICAL INTERACTIONS AND THE PRODUCTION OF APPROPRIATELY GENDERED BODIES

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE DIVISION OF THE SOCIAL SCIENCES
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

DEPARTMENT OF SOCIOLOGY

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CHICAGO, ILLINOIS
JUNE 2016

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Abstract

In this dissertation I examine the regulation of appropriately gendered bodies within the cycle of care for "female" cancers. In both the cultural imagination and in medical care, activism and treatment of gynecological and breast cancers assume an alignment between individual identity, physical body, and normative ideologies of gender. Throughout, I argue that patients with the "wrong body" for female cancers illustrate the ways in which normative gender expectations are continually (re)produced within medical interactions and contribute to inequality in health care. My analysis draws on the experiences of patients whose bodies and gender identities don't match the medical and social expectations for gynecological and breast cancer care: transgender men who seek out gynecological care, cisgender men diagnosed with breast cancer, and cisgender women with breast cancer and/or BRCA mutations who choose prophylactic bilateral mastectomies. These patients create "gender trouble" for medical professionals. That is, they challenge associations between femininity/ female bodies and masculinity/ male bodies that are taken for granted in social life generally and are naturalized through medical care more specifically. I connect the stories of these patients to show that medical care turns on whether and how an individual "counts" as a man or woman in the context of these interactions and that patient treatment options hinge on their embodied choices. Building on contemporary theories of biopolitics and ethnomethodological theories of gender, I argue that medical interactions are critical to understanding the perpetuation of gender when bodies are under scrutiny. The interview data discussed in this dissertation shows that medical interactions reproduce and legitimate cultural ideologies of gender through patient bodies. Patients both resist and rely on gender ideologies to make sense of their treatment decisions and medical care.

Acknowledgements

I began this project in earnest after leaving the urban landscape of Chicago for the low lying mountains and fields of southern Vermont. The first person I met upon moving to a tiny village on the border of New Hampshire was the manager of the local gym. Ashley was brimming with energy when I arrived at the gym for a tour and to get membership information. The only mark of the breast cancer that would ultimately take her life was a brightly patterned headscarf, donned to conceal the impact of chemotherapy. I knew Ashley for almost two years. She ran the afterschool program at the local elementary school and coached my oldest child's soccer team. She continued running (one of her many passions) even though doctors asked her to take it easy. In that first meeting she asked what I did. I told her that I was a graduate student working on my dissertation. This naturally led to a conversation about my research interests. Her eyes lit up but she didn't tell me her story. I learned it slowly, through playground conversations and chats between sets at the gym. Her death still impacts the small community in which we live even though it has been over two years since she died.

In the final phases of writing up my research, my step-father was diagnosed with cancer. His surgeries and chemotherapy occurred as I analyzed the accounts of respondents. As difficult an experience as it was for him and our family, he and my mother reminded me that the accounts that make up my data are so much more than that. Cancer touches nearly all of us. Even in a community larger than Ashley's and mine, this disease can have deep effects. It can be difficult to understand and to explain the experience. I am truly grateful to all the respondents who generously shared their stories. Theirs are stories that may reflect those of friends, family, and readers themselves. I hope that I have done them justice.

For their patience, support, guidance, and careful engagement with my work I thank my committee of mentors: Kristen Schilt, Kate Cagney, Lauren Berlant, and Monica Casper. I am also indebted to my wonderful writing group (Abi Ocobock, Alicia Van de Vusse, Amy Brainer, and Clare Forstie) for their insightful readings of various versions of this project.

Finally, I thank my spouse, Yamara, for her indefatigable support of my research and my kids, Noa and Zoe, for providing much needed comic relief and reality checks throughout this process.

Introduction

In May 2013, actor and humanitarian activist Angelina Jolie published an op-ed piece in the *New York Times* entitled, "My Medical Choice." In the article, she explained her decision to get tested for BRCA, a genetic anomaly that significantly increases a person’s lifetime risk of breast, ovarian, prostate, and pancreatic cancers. After testing positive for this genetic condition, Jolie chose to undergo a prophylactic bilateral mastectomy; a surgery to remove both healthy breasts in order to minimize her risk for eventually developing breast cancer. Jolie's essay launched a flurry of controversy, with medical professionals and other breast cancer survivors offering their opinions on her decision. Concerns in the press and the medical community centered on three main issues: whether such surgery (often deemed "radical" in the press) was medically warranted; the "perils of over awareness,” or the basing of medical decisions on fears about the potential development of breast cancer; and on the risk of "psychological harm after having radical surgery" (Davies 2013; Ferro 2013).

While every surgery has associated potential complications, the notion of psychological risks implies that something more fundamental to a patient’s identity than health is at stake in these surgeries. In the case of bilateral prophylactic mastectomies, the “harm” about which physicians are concerned has to do with the disruption of a patient’s sense of femininity as a result of the surgery, a point Jolie addresses directly. She wrote, "On a personal note, I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity" (Jolie 2013). Jolie described her bilateral prophylactic mastectomy in a straightforward manner, including her reconstruction; "Nine weeks later, the final surgery is completed with the reconstruction of the breasts with an implant. There have been many advances in this procedure in the last few years, and the results can be beautiful."

Angelina Jolie's account of her diagnosis and treatment, along with public criticism of her decisions by physicians, highlights a tension within the two main tenets of biomedical clinical practice: evidence-based medicine and patient-centered care. Put another way, the initial controversy over prophylactic mastectomies as a reasonable treatment following a positive BRCA test result illustrates a conflict between medical authority and patient agency in medical decision-making that provides a unique perspective to explore the ways in which the cycle of care for "female cancers" (i.e. breast and gynecological cancers) is embedded within the gender system. This is a puzzle about normative assumptions about gendered bodies, the role of medicine in perpetuating cultural ideologies of gender through the regulation of patient bodies, and the ways that patients (through their interactions with medical institutions) can embody resistance to or conformity with the gender structure.

In my dissertation, I investigate the regulation of gendered bodies within the cycle of care for female cancers. I focus on the experiences of 57 individuals whose bodies and gender identities do not match the medical and social expectations for gynecological and breast cancer prevention and care. I link together the experiences of transgender men, cisgender men, and cisgender women who create "gender trouble" for medical professionals because their bodies or their choices concerning those bodies challenge both standards of care for these cancers and normative expectations for gendered bodies. Building on contemporary theories of biopolitics and ethnomethodological approaches to gender (see Rose 2007; Rose and Novas 2005; West and Zimmerman 1987 and 2009; Westbrook and Schilt 2014), my research engages a pressing question within sociological and gender theory: how are normative expectations and inequalities about gender reproduced and challenged through medicalized social interactions? Throughout, I argue that medical interactions are critical to understanding the perpetuation of gender when bodies are under scrutiny and that sociological inquiries into the role of gender in medicine must empirically address gender as a process rather than as a variable determining access to medical care and health outcomes.

The Gender Problem in Medicine

In the United States clinical practice is driven by two key principles: evidence-based medicine and patient-centered care. Feminist activism and theories of gender are integral to both of these principles, yet have not been appropriately integrated into medical practice. Instead, biomedical concern for gender and health inequality has treated gender as a binary variable, rather than as a system of inequality operating at multiple levels of analysis (see Connell 2012; Hammarström et al. 2014; Springer, Hankivsky, and Bates 2012). The biomedical profession has undergone tremendous changes since the 1960s in response to gender-based critiques. However, these critiques are limited in addressing the ways in which medical care specifically is shaped by cultural ideologies of gender and in turn reinforces those ideologies.

One of the key catalysts for professional shifts in biomedicine was the Women's Health Movement of the late 1960s. Feminist activists and scholars publicly protested and critiqued the medical regulation of female bodies, the objectification of patients, and the patriarchal context in which medical care and research were embedded (see Ruzek 1978 for a detailed history). The women's health movement was largely focused on how medical care was provided and activists launched an ongoing process of altering medical interactions to shift more power and autonomy to the patient. In short, the movement sought to challenge the authority, knowledge, and power of the male-dominated and male-centered medical profession in order to empower women to gain control over their own bodies. The importance of patient knowledge and empowerment became mainstream in the two decades following the height of Women's Health activism

(Armstrong 2007). Patient-centered medicine emerged as a standard form of clinical practice that sought "to focus medical attention on the individual patient's needs and concerns, rather than the doctor's" (Bardes 2012).

Feminist activism not only emphasized the importance of subjective patient knowledge to medical care, but also significantly influenced the definition of evidence-based medicine as an approach to medical care that prioritizes reliance on empirical data for clinical decision-making. Evidence-based medicine has its origins in major shifts in the medical profession occurring in the 1960s and 1970s but did not become standard in the field until the 1990s (see Claridge and Fabian 2005; Sur and Dahm 2011). This incorporation of scientific reasoning was based largely in advances in biology and biochemistry, hence the emergence of the term "biomedicine" to designate this new approach of integrating research with clinical practice. During this time, feminist activism led to an increasing awareness about the differences in clinical and therapeutic treatments between women and men. Until the 1990s, biomedical research was conducted primarily with white, male research subjects. Those involved in the Women's Health Movement and feminist scholars questioned this research model and pointed out how this research standard led to gender-based disparities in health care access and outcomes. As a result, clinical researchers have adopted an inclusion model in which women (as well as racial and ethnic minorities) are considered crucial to the research process (Epstein 2007; Mazure and Jones 2015). Yet, the inclusion model relies on a binary, categorical understanding of gender. That is, gender is seen as an individual attribute rooted in biology and is often used as a variable in determining the outcomes of various medical interventions.

The inclusion paradigm in biomedical research also became influential for clinical practice. This change is most explicit in the emergence of gender-specific medicine (GSM), although the same ideas permeate all clinical practices more implicitly. Proponents of GSM believe that every clinical decision, every diagnosis, and every treatment must take the gender of the patient into account. Although evident across health care generally, the rise of GSM serves as a magnifying glass for the ways in which a binary approach to attending to the issue of gender in medicine influences care. This approach to medicine unquestioningly takes biological differences between men and women as the starting point for medical practice. Marianne Legato is one of the foremost proponents of gender-specific medicine (2004 and 2010). She specifies that this approach reflects the "general agreement that men and women are different, and that those differences imply that gender-specific medical care of the patient would be better than the way we've been doing business" (Legato 2004, 61). Importantly, gender-specific medicine creates a stark distinction between male and female bodies that cannot be crossed and defines appropriate medical care through these purported distinctions. Legato does not provide evidence for biological differences between men and women, but rather asserts the truth of this statement to “general agreement,” a phrase that emphasizes the ways in which gender operates as a taken-for-granted system of difference (Garfinkel 1967; Kessler and McKenna 1985; West and Zimmerman 1987).

Ellen Annandale has written extensively in critique of GSM, arguing that this approach renders social and cultural factors "virtually meaningless or framed in a highly individualized manner... The social therefore becomes a residual category that is devoid of meaning and unrelated to the wider social structural factors that impinge on health" (2009, 93). In addition, in their content analysis of medical journal articles on GSM, Annandale and Anne Hammarström conclude that the rise of gender-specific medicine has created a master discourse of the gender-specific body that is rooted in difference, reduces gender to sex, and fragments the body from social processes (2010). Importantly, the emphasis on differences between men and women takes center stage in gender-specific medicine. According to critics, this emphasis serves to reinforce a presumed natural distinction between male and female bodies.

Annandale's critique of GSM raises important questions for feminist politics and scholarship. Whereas some feminist approaches to challenging gender inequality center on the notion that biology is not destiny and that decoupling the oppressive system of gender (that which is socially constructed and changes over time) from biological difference is the path to equality, Annandale argues that the current challenge is to "appreciate that sex *and* gender are socially scripted… [and] to view the deconstruction of sex/gender as an integral part of wider social change rather than as a critical commentary on it" (2009, 106 emphasis in original). The relationship between gender and health then goes beyond simple statistical differences between men and women with respect to health care access, morbidity, and mortality. Critical examination of gender and health requires recognition that social processes shape bodies and that bodies, in turn, shape social practices. From this point follows Raewyn Connell's argument that "we cannot logically treat gender as an independent variable and health status as a dependent variable" (2012, 4). Instead, the relationship between gender and health must become more nuanced.

Connell argues that a relational theory of gender is essential to understanding this relationship between gender and health not just on a theoretical level but also for world health policy. She points out that the vast majority of global health policy relies on a categorical approach to gender, most notably in addressing disparities between women as a group and men as a group. She notes that such policies see "'women' and 'men' as fixed, unproblematic categories" and that the problem with gender comes down to a "statistical difference between these categories" (2012, 1). This is not an entirely new concept. Kessler and McKenna (1985) expressed their concern that research on gender and medicine too often viewed gender as an "irreducible fact" through which gender is defined by purported biological difference. While thinking about gender in this way has certainly led to important policy reforms across numerous institutions, categorical thinking fails to address differences within categories and, importantly, cannot conceptualize "the historical processes in gender itself, the ways gender orders are created and gender inequalities are created and challenged" (Connell 2012, 2).

The omission of relational approaches to gender presents a major obstacle in catalyzing changes in the biomedical field that will address what I and other theorists consider to be the more complex root of gender-based health disparities. Several alternative theoretical approaches to addressing the problem of gender and health have been put forth in both sociological and medical journals (see Annandale 2014; Springer, Hankivsky, and Bates 2012; Hammarström, Johansson). As Connell argues, a relational gender analysis of health questions “needs to consider simultaneously the shape of the gender order and its historical transformations, the pattern of institutional and interpersonal relations, and the body-reflexive practices in which health consequences are produced” (2012, 5). This structural and ethnomethodological approach is theoretically compelling but lacks empirical evidence to explain how this process occurs, the implications for medical practice, and the reciprocal implications of medical practice on the gender system.

Medical care is, I suggest, implicated in the reproduction of ideologies of gender as evident in growing attention to gender in biomedicine and social shifts towards biocitizenship, a concept to which I will return. The centrality of the gender-specific body to contemporary medical practice renders bodies which cross the boundary between man and woman in any way as problematic, troubling, or incompatible with medical care. The narrative accounts considered in this project concerning patients with the “wrong body” for gynecological and breast cancers indicate that processes of gender accountability and determination hinge on the alignment of individual identity, physical body, and normative expectations about appropriately gendered bodies. Throughout this manuscript, I draw on empirical data to incorporate relational theories of gender with theories of embodiment and medical regulatory power. By focusing on patients who disrupt this alignment in the context of female cancers, I raise the issue of the regulation of gendered embodiment as a critical puzzle that can illustrate the ways in which taken-for-granted cultural ideologies of gender shape and are shaped by medical interactions.

Theoretical Framework

Ethnomethodological theories of gender include an understanding of gender as a system of reality construction that organizes social life (Kessler and McKenna 1978). Subsequent theorists have taken up this line of thinking and consider the ways in which this system operates in everyday life as a set of social practices occurring at cultural, institutional, organizational, interpersonal, and individual levels (Acker 1990 and 1992; Lorber 1994; Ridgeway 2011; Ridgeway and Correll 2000 and 2004; Ridgeway and Lovin 1999; Risman 1998 and 2004). Following in this tradition, Cecilia Ridgeway notes that in social relations, the ability to classify another as a man or a woman is essential both for organizing the interaction and for organizing one's sense of self. The inability to classify another is "profoundly unsettling and, more to the point here, *disorganizing* of the social situation" (2011, 32 emphasis in original). She argues that gender is a primary category system, which organizes social relations in interpersonal interactions, organizations, and institutions. Ridgeway deploys as key evidence psychological studies that suggest a link between the ability of people to sex-categorize others and their subsequent cognitive ability (or inability) to process a given social situation (See Macrae et al. 2005; Wisecup, McPherson, and Smith-Lovin 2005).

Ridgeway argues that the primacy of gender is not simply about categorizing others but also results in a cultural requirement for individuals to perform gender. This point emerges from the "doing gender" approach conceptualized by West and Zimmerman who explained that gender is a "routine, methodical, and recurring accomplishment" (1987, 126). These individual instances of doing gender are bound to social institutional arrangements, which rely on a hierarchical understanding of gender. In contrast to earlier socialization theories, which argued that gender is a process that occurs early in life and remains constant throughout adulthood, West and Zimmerman argued that gender is a socially constructed category that is continuously (and often subconsciously) reproduced in all social contexts and throughout all social interactions.

People do gender in interactions in order to be socially comprehensible. West and Zimmerman explained this in terms of the concept of "accountability." People are expected to behave in ways that are in accordance with cultural expectations for their sex category. In social interactions we present visual cues to indicate our belonging to a sex category. We are then assessed by others in social interactions based on our compatibility with "the 'essential natures' of—a woman or a man" (West and Zimmerman 2009, 114). Laurel Westbrook and Kristen Schilt extend the analytic possibilities of doing gender by adding their concept of determining gender. According to Westbrook and Schilt, "in face-to-face interactions, determining gender is the response to doing gender (2014, 33). Specifically, determining gender involves the interpretation of another person's gender cues and the placement of a person in a gender category. It is the process by which accountability is assessed. There are two key criteria for determining gender offered by Westbrook and Schilt: identity-based and biology-based. Identity-based criteria turn on a person's claims to identity while biology-based criteria refer to supposedly unchangeable physical characteristics from secondary sex traits to chromosomes.

Unlike West and Zimmerman's discussion of accountability, the centrality of the body is emphasized in the determining gender concept. Westbrook and Schilt's theoretical work is based in empirical analysis of moments of ideological collision where identity- and biology-based criteria clash. They specify that these are moments when "a great deal of biographical and bodily knowledge is known about the person whose gender is in question" (2014, 33). In everyday social interactions, the body is merely implied. Processes of determining gender and gender accountability are based on visible gender cues that imply certain biological characteristics, particularly genitals. Westbrook and Schilt focus on moments of ideological collision where the accountability of transgender people to gender categories is questioned. They argue that this allows for an examination of the ways in which "gender attribution challenge[s] or maintain[s] the sex/gender/sexuality system" (Westbrook and Schilt 2014, 34). It is not only transgender or gender non-conforming people who experience these ideological collisions, however. Cisgender people can experience these ideological collisions as well when their bodies and identities fail to align in culturally expected ways either by virtue of their personal choices or due to the experience of disease. The medical context serves in my research as a moment of such ideological collision. In this context not only are biology-based and identity-based criteria for determining gender in conflict, but the role of medical providers in legitimizing certain combinations of bodies and identities becomes evident.

The process of determining gender occurs in the context of "a social system predicated on clear, fixed distinctions between men and women (Westbrook and Schilt 2014, 37). This social system not only shapes the doing and determining of gender, but also is reinforced by these processes. According to West and Zimmerman, “doing gender means creating differences between girls and boys and women and men, differences that are not natural, essential, or biological” (1987, 137). This distinction is the foundation of gender-specific medicine in particular and biomedicine more generally. Medical professionals play a key role in legitimizing the gender structure through biomedical means. Unlike most social interactions, it is important that in medical care the body is scrutinized. Whereas gender determinations are typically made with only hypothetical knowledge of a person’s body, in medical interactions the “reality” of the gendered body becomes central to medical decision-making.

Medical care is fundamentally a matter of face-to-face interactions and as such, the ethnomethodological concept of “doing gender” and the subsequent body of empirical, theoretical, and critical research that the concept spawned are instructive in unpacking the ways in which medical care is shaped by ideas about gender but also reproduces those beliefs through the bodies of patients. Bodies are implicit in relational theories of gender but need to be at the center of analysis of empirical studies of gender in medicine because medical interactions are defined through the examination of the body. As Connell notes, the physical sense of maleness and femaleness is central to the cultural interpretation of gender” (1995, 52-53). Further, Connell posits that social structures emerge from social practices and that these social practices occur on and through the body and embodied experiences (1995, 94).

Returning to Westbrook and Schilt’s criteria for determining gender, it is clear that identity and biology can lead to conflict in the determination of gender. I contend that biology-based criteria emerge primarily from medical authority that serves to naturalize and normalize distinctions between men and women based on the physical body. Despite the power of interactionist and relational theories of gender, these frameworks are insufficient for understanding interactions in which the body is fully on display. Medical interactions thus present an opportunity to more critically examine the tension between identity-based and biology-based criteria for determining gender and to explore the role of medical providers, as authority figures, in perpetuating the gender system as well as the ways in which patients, through their bodies, can reconsider the relationship between what it means to be a woman or a man and the physical body.

Medicine is a particularly important context to understand the relationship between ideologies of gender and embodiment. Health and wellness are increasingly integral to social life in general. Political scientist Nikolas Rose argues that in contemporary society, corporeality is essential to personal and social practices of identity and that as citizens, individuals have a set of biological responsibilities regarding health behaviors. He borrows the term “biocitizenship” from Adriana Petryna (2002) to argue that the health behaviors of individuals are deeply political acts with repercussions for society as a whole. Underlying biocitizenship is the idea that as shifts in biomedicine occurred and empirical research began to drive clinical practice, "biological presuppositions, explicitly or implicitly, …shaped conceptions of what it means to be a citizen, and underpinned distinctions between actual, potential, troublesome, and impossible citizens" (Rose 2007, 132). Importantly, biocitizenship is linked “to beliefs about the biological existence of human beings, as individuals, *as men and women*, as families and lineages, as communities, as populations and races, and as a species" (Rose 2007, 132, emphasis added).

The presumed differences that are naturalized through processes of doing and determining gender within medical interactions support contemporary forms of citizenship. The role of medicine in this system is not “focused on eliminating pathology to protect the destiny of the nation. Rather, it is concerned with our growing capacities to control, manage, engineer, reshape and modulate the very vital capacities of human beings as living creatures" (Rose 2007, 11). Social life is specifically characterized by *beliefs* about men, women, and their respective bodies that are relational, controllable, and transformable primarily through medical interventions. This is a critical point that creates a theoretical opening for understanding the relationship between medical care and gender, and for identifying points of resistance and transformation within the gender system. It is my contention that what Rose calls a new mode of vital politics is not only acting on the level of individual bodies, but also on the level of social organization itself. This ability to mold, control, and manage the "vital capacities of human beings" through medicine is shaped by and reinforces cultural ideologies of gender through interpersonal interactions in the clinical setting (rose 2007, 11). Biomedicine, is thus an institution of social control that is embedded within the gender system and reinforces this system through the interactional environment of medical care.

A person's accountability to gender ideology, in the context of biocitizenship, is linked to standards of medical care. To be a good biocitizen requires adopting certain health behaviors including submitting to medical exams. This care is predicated on differences between male and female bodies that are naturalized through social interactions and legitimized through the institutional practices of the medical profession. Legitimacy is fundamentally a question of being counted, and as such of being accountable. In their review of sociological understandings of legitimacy, Johnson, Dowd, and Ridgeway show that the processes by which social objects (including people) become legitimate turns on the ways in which individual behaviors become oriented to taken-for-granted cultural norms and beliefs (2006). Among the various definitions of legitimacy used within sociology, these authors make note of several similarities. Legitimacy is a distinctly social process whereby social actors (individuals, organizations, or institutions) become oriented to taken-for-granted cultural norms and are judged legitimate (or not) by other social actors. Cultural beliefs, in short, create expectations for behavior and an individual's ability to meet these expectations determines legitimacy. Critically, an individual does not need to believe that these expectations or norms are personally desirable, what Weber calls "propriety." Rather, cultural norms can influence legitimacy simply because an individual believes that they are obliged to adhere to them, a process Weber terms "validity" (see Johnson, Dowd, and Ridgeway 2006, 55). Various authorities support the process of validity, thus perpetuating the cultural norms.

Doing gender then can be understood as a process of legitimation because individual behavior and social interactions occur in a context of cultural expectations about what it means to be a woman or a man in social life. While Johnson, Dowd, and Ridgeway suggested that legitimacy is often about influence and status, I argue that it is a matter of being socially visible. One of the most important authorities in this process of legitimacy are physicians because gender is so deeply tied to the visible cues of the body. From the moment of a person's birth, physicians have the authority to assign a sex (based on the visible body) that is supposed to then determine our gender. This process of legitimacy hinges on the body, a point that Didier Fassin has termed "bio-legitimacy" (2009). In sociological research, legitimacy is typically granted through institutions. I contend that more intimate, interpersonal interactions, are also critical to processes of legitimacy. In the case of gender, some of the most influential interactions occur within the medical context. Although the concept of doing gender is essential in understanding social interactions, it cannot account for interactions when the body is under scrutiny. Such interactions require additional concepts to frame analysis. Given the importance of the body to processes of legitimacy generally, if we understand doing gender as a particular form of legitimacy, and accept that physicians are one of the most important authorities on who counts as a man or a woman, then we *must* more thoroughly account for the body as a visible, affective, component of doing gender. Given this framing, it is essential to also consider health as another cultural expectation against which legitimacy is determined. The medical context is unique for the process of doing gender. In a medical exam, the body is examined. Instead of visual cues and hypothetical knowledge of the body, the body is on display. In this setting, a body may be compliant and align with implicit expectations about patient gender, patient body, and disease, or the body might be “wrong” or misaligned. Gender and health then serve as mutually reinforcing cultural ideologies that are made real through the bodies of individuals. When it comes to who counts as a woman or as a man, I suggest that medical interactions are among the most significant for determining a specific type of legitimacy which I call *social bio-legitimacy.*

Bio-legitimacy

Bio-legitimacy is a term coined by Fassin through his analysis of HIV positive African immigrants to France (2000 and 2009; Fassin and D’Haullin 2005). Fassin makes the case that due to their status as suffering bodies, these immigrants are granted legal status. They are made *bio-legitimate*. Through the political process of bio-legitimacy, the bodies of these immigrants are 1) made visible and 2) provided a legal (and social) status within the borders of France. Fassin’s project is aligned with the work of Rose on bio-citizenship. Where Fassin focuses on how an illegitimate body becomes legitimate through political and migratory processes, Rose attends to the process by which any member of society is deemed worthy of citizenship. This process includes a set of rights and responsibilities (specifically pertaining to health) with which to determine citizenship and once given this status, citizens are then accountable to these expectations for health behaviors.

Throughout this manuscript I extend Fassin's concept of bio-legitimacy by arguing that 1) bio-legitimacy is a distinctly social process that can be achieved through medical interactions, 2) these interactions are embedded within the sex/gender/sexuality system, and 3) that bio-legitimacy occurs in a context of ideologies of gender. I offer the term social bio-legitimacy to bring to light the role of interpersonal interactions and cultural ideologies of sex/gender/sexuality that are an absent presence in the initial conceptualizations of bio-legitimacy and bio-citizenship. I add "social" to Fassin's concept to make explicit the role of social structures (particularly gender) in medical interactions and to the reciprocal role of these interactions in perpetuating the gender system.

At the core of social bio-legitimacy is the notion that social life depends on the visibility of gender. Social legitimacy turns on processes of doing and determining gender, but the ability to be seen and to be recognized as a man or woman begins with medical interactions. This legitimacy is generally unquestioned for the average citizen unless their appearance or behavior is dissonant with normative social expectations (i.e. gender non-conforming). In the case of trans individuals, medical professionals can confer social bio-legitimacy through surgery, hormones, and mental health evaluations – though, as research shows, they can also withhold legitimation of trans people's identities (see Spade 2003). Disease can also create a legitimacy crisis for cisgender individuals. Breast and gynecological cancers can create these liminal moments where individuals who never questioned their personal or social gender identity may have their gender questioned (see for example Elson 2004). The medical cycle of care for these cancers not only identifies, prevents, and treats these diseases but it also reinforces normative expectations about male and female bodies because the interactions through which care is provided are deeply shaped by these very expectations. The response of medical authority to the ideological collision that occurs when a patient's body or identity are "wrong" for the care in question is an opportunity for linking West and Zimmerman's concepts of doing gender and gender accountability to Westbrook and Schilt's exploration of determining gender and to theories of biopolitics. These processes become particularly relevant for understanding challenges to and maintenance of the gender system because the cultural authority of the medical profession serves to bolster or undermine the social bio-legitimacy of patients. In assigning social bio-legitimacy, medical providers not only draw on cultural expectations of normative bodies, but also reassert their power in social life, thus maintaining the gender system in light of the challenges posed by patients with the wrong body.

The Case of Gynecological and Breast Cancer

Second only to heart disease as a leading cause of death (National Heart, Lung, and Blood Institute 2010), cancer (particularly gender-specific cancer) has an extraordinary degree of visibility in the United States. Our collective fear of these cancers, and their combined media prominence, place gender-specific cancer at the center of health policy, individual health behaviors, and cultural life. [1] Gender-specific cancer has been taken up by sociologists typically to explore the ways that hegemonic gender norms shape how women and men respond to their diagnosis and treatment options, as well as public discourse about these diseases (see, for example, Casper and Carpenter 2008; Hesse-Biber 2014; Oliffe 2009; Sulik 2011). While such studies do not discount individual agency, they inadequately analyze instances of individual resistance and regulatory disruption. Patients typically behave in ways that are predictable given

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[1] Gender-specific cancer is an umbrella term for gynecological, breast, prostate, and testicular cancers. It is imprecise as breast cancer occurs in both men and women. However, this term does indicate the common assumption that these diseases only occur in specific bodies. As such it is a useful frame for exploring how some individuals are interpreted as having the wrong body for cancer care. "Gender-specific cancer" is not used in any official context but does appear in several journal articles (for example see Baker et al. 2009; Mercadante et al. 1997; Orsi et al. 2007). This term is also used in lay information. The website for the Cancer Treatment Centers of America (www.cancercenter.com), an important resource for individuals seeking treatment, employs this term.

the constraints of the gender system. With respect to gender, we expect to see people maintain the system, but what might resistance look like and what are potential threats to the system? Those social interactions that trouble the system are the foundations for understanding change. If we seek to alter the reality of gender inequality in medical care, we need to begin research at these points of gender trouble because they can illustrate the often invisible influence of cultural ideologies of gender on medical care. Analyzing the way these ideologies are made real through medical interactions allows us to better understand how these ideologies in turn shape gender inequalities in health.

Ongoing controversy regarding the diagnosis, treatment, and recovery processes advocated by medical institutions point to the importance of social structures in accessing medical interventions. Cervical cancer, for example is the easiest female cancer to prevent given the effectiveness of the Pap test for precancerous cells and the FDA approval of the Human Papilloma Virus (HPV) vaccine in 2006 (Centers for Disease Control 2010a; Federal Drug Administration 2015). While the efficacy of the Pap test and the HPV vaccine in preventing cervical cancer are well established, the uptake of these interventions by the general public has been limited. Illustrating this point, the percentage of women who reported receiving a Pap smear within the last three years declined between 2000 and 2008 (Centers for Disease Control 2010b).[2] Both of these interventions are politicized and render female bodies and sexuality as fodder for intense public debate (Casper and Carpenter 2008; Casper and Clarke 1998; Wailoo et al. 2010). What is at stake for individuals in adopting these technologies is fundamentally related to the tension between gender structures and agentic bodies, not just inequality in access.

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[2] Although it is beyond the scope of this chapter to speculate about why this decline has occurred, I suspect that a partial answer may be found by considering the ways in which these diseases/ interventions are racialized and sexualized.

In contrast to the relative success in decreasing mortality from cervical cancer, breast cancer has the highest mortality rate of gender-specific cancers. A great deal of scholarship has attended to the biopolitical culture of breast cancer activism querying why the movement became so successful and what such activism means for knowledge, agency, and the body (see for example Kasper and Ferguson 2000; King 2006; Klawiter 2008). Through the activist discourse, securing research funds and advancing scientific knowledge become key weapons in a war on the epidemic of breast cancer. Typically gender and sexuality become the frameworks through which these controversies and politics are understood. Breast and gynecological cancers become experiences of liminality that require a renegotiation of one's sense of self (Little et al. 1998). This renegotiation hinges on the restoration of a woman's femininity through embodied practices.

One example of using body practices to restore femininity is the American Cancer Society's "Look Good … Feel Better" campaign. Developed in 1989 by the Personal Care Products Council Foundation, Look Good Feel better programs are designed to improve "self-image and appearance through … beauty sessions that create a sense of support, confidence, courage, and community" (The Personal Care Products Council Foundation 2015). Catharine Phillips is particularly critical of the collaboration between the cosmetic industry and the American Cancer Society given the heavy emphasis on using potentially toxic (and by extension carcinogenic) cosmetics to "heal" the self-image of a breast cancer survivor. Phillips makes clear the conflicting role of femininity in the narrative of cancer recovery in this program specifically and in breast cancer awareness discourse generally. She notes that there is a possible link between an excess of estrogen (the female hormone) with the development of certain cancers. In other words, possessing too great a quantity of estrogen (i.e. a biological indicator of femininity) leads to cancers which assault one's feminine identity by destroying breasts. The means by which to recover from this destruction is through the application of cosmetics, which, Phillips argues, can themselves lead to cancer by virtue of the toxic chemicals used in their creation.

The efforts of Look Good Feel Better center on the belief that femininity is disrupted through breast cancer. This disruption combined with fears about mortality are central to Dorothy Broom’s understanding of breast cancer. Broom argues that not only is the fear of death and disease a central frame for the experience of breast cancer; but also that fears about sexuality and femininity shape the experience, decision-making processes, and narratives told about breast cancer. Broom identifies four discourses common to the breast cancer experience: morbid fear of death and disability, infiltrating destruction from within, femininity deranged, and the destruction of heterosexual availability. The latter two discourses in particular should come as no surprise given the hegemonic nature of femininity and heterosexuality so well-articulated by feminist theorists (see Schippers 2007). Although scholarly research into breast cancer experiences has proliferated since Broom's writing, the discourses she identifies remain useful for analyzing not only narrative accounts of breast cancer but also for understanding the ways in which gender ideologies impact both the experience of cancer and the care received by patients.

Identity and the restoration of femininity appear in most contemporary studies of breast cancer. Restoring femininity through bodily practices becomes the key means by which women reconcile their sense of themselves as women with the ravages of cancer. Research on this theme tends to affirm hegemonic notions of femininity. Potts' (2000) study of autobiographical writings of women with breast cancer notes that women make sense of their experience by turning to mainstream conceptions of feminine beauty. 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). This was the case because the breast is crucial to womanhood. Ericksen writes, "No matter how they responded to breast cancer diagnosis or how much authority they gave doctors, women found the reality of a deformed or absent breast traumatic" (2008, 156).

In her influential study of breast cancer activism, Gayle Sulik asserts that breast cancer is "a new American religion just for women" (2011, 4) that is "grounded in … deeply held beliefs about gender and femininity" (2011,9). Breasts in this new religion have a great deal of symbolic importance. These body parts are celebrated as the principle symbol of womanhood, motherhood, and female sexuality" (Sulik 2011, 14-15). Relying on normative conceptions of femininity based in a binary gender system serve to “to recast the uncertainty of illness into something more manageable and valued” (Sulik 2011,74). In everyday life, breast cancer awareness slogans such as “Save the Ta Tas,” “Save Second Base,” and the proliferation of pink paraphernalia in October indicate threats to female embodiment and heterosexuality, as well as indicate that reinforcing femininity is the means by which to recover from this disease. Gynecological cancer activism draws on similar narrative tools, such as the “Turn it Teal” and “Teal Heels” campaigns (represented by a teal high heel shoe with gynecological cancer facts) as well as slogans that implore women to “check their box” and to “help the hoo-hahs.” These cancers, because they are primarily diagnosed in cisgender women, draw on tropes of femininity to mobilize research funding and public awareness.

Breast and gynecological cancers are unique windows into the cycle of medical care. At each point in the cycle of care (i.e. early detection/prevention, diagnosis, treatment, and recovery) biomedical intervention is standard. Bodies assigned female at birth are routinely subjected to medical screenings to catch cancer as early as possible. Pap smears, the extraction of cervical cells via scraping, are the only medical intervention that can identify and eradicate precancerous cells, thus effectively preventing cervical cancers. Mammograms are a part of standard medical care for women in order to catch breast cancer early. Female cancers are unique in this respect. Although testicular exams are a part of medical care for cisgender men, they are not effective as an early detection measure, with most of these cancers "caught" by men in every day, non-medical situations. Prostate exams also exist, yet these are particularly controversial. These exams typically consist of a blood test for prostate specific antigens (PSA) and manual exams. Neither of these are particularly good predictors of cancer, with PSAs having a particularly high false positive rate. Additionally, the slow growing nature of prostate cancer rarely causes death. Men generally die with prostate cancer rather than because of it. As a result, treating prostate cancer remains medically controversial (Hoffman 2015).

Female cancers thus allow for the examination of gender ideologies on all phases in the medical cycle of care because medical interventions are standard at every point in the cycle. This cycle is not specific to cancer. Instead, it is the cycle of prevention and treatment that characterizes medical care. In both the cultural imagination and in medical care, the narrative of female cancer assumes a "right body" for care that is aligned with a female identified, cisgender woman, with normative desires for her body's appearance. When a patient does not meet these assumptions, they create gender trouble for health care providers. Interview data from such troubling patients identifies the importance of normative expectations for gendered bodies to medical care and the ways in which such care reinforces the legitimacy of these expectations.

Project Design and Overview

In order to understand how medical care is shaped by and in turn shapes normative expectations for gendered bodies, I selected cases at each point in the cycle representing individuals with the wrong body for care, that is their bodies, desires for their bodies and/or gender identities don't match the medical and social expectations for gynecological and breast cancer care. For the prevention stage, I interviewed 13 transgender men about their experiences with preventive gynecological care (individuals whose gender identity is different than the sex assigned to them at birth). At the diagnosis and treatment stage, I interviewed 11 cisgender men about being diagnosed with and treated for breast cancer. Finally, I interviewed 33 cisgender women about their decisions to pursue bilateral mastectomies in the wake of a breast cancer or BRCA diagnosis. Additionally, these women explained their decisions about reconstruction after mastectomy as part of the recovery process.

I conducted in-depth, narrative interviews with these 57 individuals aged 22-71. Interviews occurred in person, over video conference (i.e. Skype or FaceTime), and over the phone. Participants chose the time, method, and location for the interview. In a few cases, follow-up correspondence occurred via email. Several participants also kept personal blogs. These resources were useful tools to check participant recollections at the time of the interview with blog entries posted during their treatment. For those participants with blogs, I had a historical source to confirm their memories. Participants were self-selected and responded to calls for participants placed through social media (Facebook and Twitter) after identifying organizations and groups that serve the research populations of interest. I also found several participants through snowball sampling. Having moved to a new location just prior to beginning research I was often asked what I did for a living. When I explained my research, I was often directed to a friend or family member who fit the study criteria. These individuals then were able to provide additional contacts to additional friends and family. My sample represents a conservative test of the problems of gender and the body for medical practice and gender theory.

This is a privileged sample: white, middle-class, employed, insured, and well-educated. These are the individuals who *should* have the most power to advocate their desires in medical interactions, but my research shows that this is not the case.

Chapter Organization

In Chapter One, "Prevention and Early Detection," I address the first phase in the cycle of cancer care: prevention and early detection. As I show, cancer prevention has two central approaches. The first focuses on patient behaviors: not smoking, eating or not eating certain foods, exercise, taking certain supplements, etc. The other approach is distinctly biomedical and includes regular physical exams, screening tests (PSA tests, Pap smears, mammograms, etc.), and/or HPV vaccines. Drawing on the experiences of transgender men seeking gynecological care, this chapter develops the argument that assumptions about gendered bodies are at the heart of preventive care for "female" cancers in ways that can have problematic repercussions for patients. The decisions of these men concerning gynecological care reflect the ambiguity of body parts to gender identity, and the ways in which gender is continually negotiated through medical interactions. This chapter also introduces the concept of elective surgery as cancer prevention. Through medical standards of care advocating for hysterectomies as a suitable alternative to Pap smears for trans men, I show that this recommendation reflects neither evidence-based medical standards nor do they necessarily fit the precept of patient-centered care. Rather, the experiences of trans men with gynecological care and medical standards advocating the removal of purportedly female body parts from trans men reflect the ways in which not only is medical care embedded within cultural norms of gender but the ways in which care reinforces normatively gendered embodiment. Ideas about masculinity and femininity along with the taken-for-granted ways these norms shape bodies significantly influence every aspect of gynecological care, from the office space to the treatment itself.

Chapter Two, "Diagnosis and Treatment," examines the experiences of cisgender men with breast cancer. I argue that the case of male breast cancer illustrates the ways in which normative masculinity is deployed by patients and physicians to manage male bodies in the distinctly feminized spaces of breast cancer care. The experiences of cisgender men serve as a direct contrast to those of the trans men in Chapter Two. Both patient groups are men entering into distinctly feminine forms of health care. In each case norms of masculinity shape the ways these patients are treated by health care providers. In the case of trans men, masculinity becomes an obstacle to care while for cis men, masculinity becomes (in most cases) a tool with which providers put men at ease. This chapter introduces the concept of choice as major theme of this research. Those patients who choose to alter their bodies in ways that challenge normative assumptions about gendered bodies are suspect and problematic within health care interactions. When bodies challenge these norms by an accident of nature (i.e. cancer), then these normative assumptions can help organize the health care interaction and direct care in ways that reinvest bodies with “appropriate” normative femininity or masculinity.

In Chapter Three, "Choosing Mastectomy," I explore the ways in which cisgender women make decisions about bilateral mastectomy. The narratives act as a rebuttal to medical research suggesting that patient quality of life concerns are an invalid justification for choosing mastectomy. Here, cis women who had heretofore inhabited the right body for breast cancer treatment can find themselves suddenly in the "wrong body" when they request mastectomies before it is medically warranted in the eyes of doctors. I explore the concept of a body out of control and the ways in which patients attempt to regain various aspects of control during the treatment process. Choosing mastectomy was symbolic of taking control of a situation in which the body is understood to be out of control. This framing of control stands in contrast to medical researchers who frame this decision as a matter of quality of life, which is then trivialized in the literature. These women understand mastectomy as a way to take control of a situation on their own terms rather than cede control of their bodies to physicians or to fate. Following the theoretical insights from Chapter Two, I explore the differing experiences of BRCA positive women and those of women with breast cancer pursuing prophylactic mastectomies (removal of the breasts in order to prevent rather than treat cancer). Although the rationales given by both groups of women are strikingly similar, contralateral mastectomies are more controversial than prophylactic bilateral mastectomies. The concept of choice is again informative here. Women with breast cancer who elect to undergo contralateral mastectomies are framed medically as acting without full understanding of their medical risks. I argue that when the experiences of this group of women are compared with those of BRCA positive women, it reveals the ways in which ideologies of gender rather than medical evidence are at the root of the differing medical approach to very similar surgeries. This is particularly evident when combining the mastectomy procedure with narratives of breast reconstruction.

In the final chapter drawing on interview data, "Reconstruction and Recovery," I examine how participants make sense of their bodies after cancer and how they come to understand their bodies as "right" despite their treatment experiences. Concern for how one is seen by others permeated the interviews. In this chapter I will explore the impact of visible changes to gender laden body parts and ask what changes (in terms of identity, social relationships, etc.) when the body changes? Across medical, social/ public, and intimate experiences, participants often faced situations where they were uncertain if and how they would be seen by others. Central to this chapter is the importance of having self-image reflected back socially and intimately, and fear of what the social world will see upon viewing an atypical body. This chapter also contributes to feminist debates about the meanings of beauty and to conversations among body scholars about bodily integrity.

In the Conclusion, I return to considerations of health, gender, and social bio-legitimacy. I reassert the utility of social-biolegitimacy as an organizing concept linking scholarship on gender, embodiment, identity, social recognition and health. I summarize the findings of previous chapters, outline directions for future research, and reassert the ways in which medical care and the gender system are mutually constitutive.

Together, these cases are a unique perspective into processes by which identity, bodies, and medical care are relationally constituted as well as to provide insight into why certain bodies create such “trouble” for the institution of medicine. The ways in which trans men, cis men, and cis women navigate medical care for body parts that are imbued with gendered meanings makes clear that medical care in practice, policy, and theory needs new tools for making sense of gender in order to improve access to and experiences of medical care. Throughout, I argue that medical care is largely shaped by commonly held beliefs about what it means to be a woman or a man and how those meanings map onto and shape the physical body. These beliefs, on the part of providers, shape gender. Gender is not a variable determining access to care and health outcomes nor is it an individual attribute. Instead medical practices are embedded within the gender system and as such are influenced by cultural ideologies of gender. Medical care is both shaped by ideas about gender but also reproduces those beliefs through the bodies of patients. I also argue that medical care is instrumental in determining which combinations of bodies and identities are legitimate or socially intelligible. By using medical language to justify normative expectations of gendered bodies, not only do medical interactions regulate patient bodies but they also mark certain bodies as legitimate while others are marked as illegitimate or wrong. The narrative accounts considered here concerning patients with the wrong body of gynecological and breast cancers indicate that processes of gender accountability and determination hinge on the alignment of individual identity, physical body, and normative expectations about appropriately gendered bodies. By focusing on patients who disrupt this alignment, I raise the issue of the regulation of gendered embodiment as a critical puzzle that can respond to both the critiques of medicine put forth by gender theorists. I argue that we need to better understand gender as an embodied process in order to rethink the ways in which the gender system is recreated and resisted, as well as to more clearly theorize the linkages between levels of analysis in the gender system.

Chapter 1

Prevention and Early Detection

Gynecology is amongst the most effective medical specialties in the early detection of cancer. The Papanicolaou (Pap) smear in particular has become the gold standard of cancer prevention (Casper and Clarke 1998). Aside from limiting environmental exposure to certain toxins (e.g. avoiding smoking to prevent lung cancer), the Pap smear is one of the most significant medical interventions into the early detection of cancer. The American College of Obstetricians and Gynecologists (ACOG) recommends that all women (by whom they mean any individual with a cervix) should begin cervical cancer screening (via the Pap smear) at age 21 and repeat the test every three to five years.[1] After age 30, ACOG suggests that women add the human papillomavirus (HPV) test as well.

Until the 2000s, the medical community lacked clear guidelines concerning gynecological care for transgender men. The documentary *Southern Comfort* tells the story of Robert Eads, a transgender man denied care for ovarian and cervical cancer (Davis 2011). When Eads transitioned from female to male in the 1980s, he was no stranger to preventive gynecological care; he had given birth to two children in the 1970s. After his transition, however, he never sought out such care again as the potential risks of "female cancers" for trans men were understudied and deemed unlikely by doctors of the time. In the mid-1990s, Robert Eads presented at an emergency room at the urging of two friends because of severe vaginal bleeding

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[1] Despite the public health benefits of Pap smears, the Centers for Disease Control (CDC) reports that the number of cisgender women who are not tested is increasing (CDC 2013). Part of this incline may be due to changes in recommendations regarding the frequency with which individuals are advised to have Pap smears. Since 2003, the recommendation has steadily decreased from once a year, to at least once every three years, to the current once every three to five years recommendation (Parker-Pope 2012). This is good news for those who dread the exam, but increasing the latency period also makes it easy to keep pushing back the exam. Concern over the frequency with which women participate in these exams has led to several studies designed to identify barriers to participating in Pap smears and other screenings.

– a symptom of what was ultimately determined to be ovarian cancer. Two dozen doctors in the region of the South in which he lived refused him treatment on the basis of being a man – and therefore having the “wrong body” for preventive gynecological care.

Since the mid-2000s, many physicians have begun to acknowledge that health care providers should encourage transgender patients to access physical exams for the body parts they have regardless of the gendered meanings associated with those parts (see Eyler 2007). In 2011, for example, ACOG released official statements about the importance of gynecological care for trans men and increasing provider “cultural competence” regarding trans patients (ACOG 2011a and 2011b). Concern for cultural competency is central to improving medical care for gender and sexual minorities. According to the Institute of Medicine's Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues, "transgender people often have negative experiences when interacting with health care providers who lack the cultural competence to respond sensitively to their health concerns" (IOM 2011, 225). "Cultural competency" is a topic of great interest in the medical community and is one component of a general shift to patient centered medicine (see Armstrong 2011). In health care settings, cultural competency refers to "the ability of systems to provide care to patients with diverse values, beliefs, and behaviors" (Betancourt, Green, and Carrillo 2002). The emphasis for physicians is on accounting for issues of diversity in their patient populations in order to increase patient compliance with medical recommendations. The care of transgender patients is made even more complicated because not only do health care providers tend to lack knowledge and training in the treatment of transgender patients but some providers also express general discomfort with this population (Cochran et al. 2007; Lurie 2005). The trouble with cultural competency within gynecology specifically is that embedded in the concept is the assumption that there is a shared system of values, beliefs, and behaviors amongst transgender patients and that this system is unique from that of cisgender patients, who presumably have some shared system by virtue of being female. If a patient embodies resistance to the assumptions through their choices about their body, then they remain outside the realm of what is imaginable within gynecological care.

The effort to improve cultural competence is complicated by a lack of empirical data articulating the range of opinions and experiences that trans men have concerning gynecological care. One discussion of gynecological care for trans men written by gynecologist Michael A.A. van Trotsenberg, relies heavily on assumptions about trans men's relationships to their bodies. In his summary of genital medical care for transgender patients, twice makes the assumption that "the majority of FtMs are virgins," by which he means that they have never had penis-vagina intercourse (2009, 242). In addition, he explains that trans men are uncomfortable with gynecological exams because "the exposure of the disliked genital tract is felt as unbearable" (2009, 242). Although van Trotsenberg fails to cite any evidence to back up these claims about the experiences of transgender men with gynecological care, his framing of the issue along with statements acknowledging patient anxiety by ACOG and Eyler locate the problem of gynecological care for transgender men within the patient. It is not the medical interaction of the exam that is problematic in these writings, but, rather it is the attitude of trans men toward preventive gynecological care.

One solution to this assumed anxiety and body dysphoria is a hysterectomy (see Eyler 2007; van Trotsenberg 2009). van Trotsenberg is such a proponent of hysterectomies that he states that "only for FtMs postponing or refusing hysterectomy and with a history of sexual activity should routine cytological screening (pap smear) be recommended according to the guidelines of the national societies of obstetrics and gynecology" (2009, 242). This framing positions hysterectomy as a solution to anxiety about both routine exams and potential future medical risks (namely cancer) as well as, at least according to van Trotsenberg, an expected component of medical gender transitions. Importantly, organizations like ACOG and the World Professional Association for Transgender Health (WPATH) take a more measured approach to hysterectomy, describing the surgery as one among many options for addressing a patient's sense of gender dysphoria.

According to the medical narrative of body dysmorphia (colloquially, the experience of being "trapped" in the wrong body), transgender men are not typically expected to want breasts or internal reproductive organs.[2] Yet, in an era of biocitizenship, individuals are expected to seek out routine preventive medical care. Trans men then are at once expected to reject those body parts associated with being female but at the same to submit to medical care for those same parts, thus accepting or at least acknowledging them. Gynecologists, in turn, are implicitly trained to treat women as more than just a set of body parts. This sets up a double bind for both patients and providers. Trans men are expected (and encouraged through public health campaigns in some cities) to participate in Pap smears and pelvic exams, yet are also expected to be uncomfortable with gynecological care due to a presumed sense of body dysmorphia. From the medical perspective, elective surgery (hysterectomy) is a reasonable course of action. Interviews with trans men suggest that a variety of strategies other than surgery may be employed and that the removal of ovaries, uterus, and fallopian tubes may not be the most desirable outcome for many men. For these men it is possible to both be uncomfortable with gynecological exams and have no interest in surgery because these body parts have been integrated into a man's identity,

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[2] The idea of body dysmorphia as a key symptom of gender dysphoria is beginning to change. In the WPATH Standards of Care, medical interventions that alter the body (i.e. hormone treatments and surgeries) are described as merely options, not a proscribed course of treatment. Instead, the guidelines produced by WPATH are explained as "flexible" and that medical approaches need to be "individualized" (Coleman et al. 2012).

are disconnected from his sense of self, because the surgery is financially out of reach, or there is a possibility that the individual may eventually want to become pregnant.

Gynecological health is framed within the medical field as a distinctly normative state of being (see Metzl 2010). The goal of preventive medical care is not only to ensure that patients occupy a physical state of health, but also to perpetuate a cultural ideology about which bodies count as healthy. The ideology of health bodies is deeply intertwined with ideologies of gender. The new paradigm of health ushered in by the Women's Health Movement incorporates patient-centered care, disease prevention, and a neoliberal approach to health care prioritizing individual responsibility, has been the source of much criticism (see Moore 2010, and Kirkland and Metzl 2010). Moore argues that underlying the new paradigm of health are gender norms that privilege normative femininity over hegemonic masculinity and that "the healthy citizen exhibits traditional feminine attributes" (2010, 107). The practice of medicine, in the effort to promote health, in fact reinforces cultural norms of femininity and masculinity. Rather than engaging with an individual's sense of what a health problem requires in terms of care, repair, and identity affirmation, medicine seeks to remove the problem. In the case of trans men, the presence of internal reproductive organs within a man's body creates a problem for a health care system invested in reinforcing norms of femininity. The easiest solution is simply to remove the problem.

Although hysterectomy is a reasonable recommendation for many, the general acceptance of hysterectomy as the solution to the problem of gynecology may obscure the gendered dynamics of gynecological (as well as other preventative) care. As Dean Spade argues, the "medical approach to [trans] gender identities forces us to conform ourselves to medical providers' opinions about what 'real masculinity' and 'real femininity' mean" (2003, 29).

Fundamentally, gynecological care is organized around a set of assumptions about identity and bodily desires. These assumptions not only impact the care experiences of trans men, but also are fundamental to medical interactions for cis and trans patients alike. These beliefs on the part of medical professionals create conflict between providers and patients when these assumptions prove to be false. At the heart of this puzzle are assumptions about what it means to be a man or a woman and how those identities relate to the physical body. In the previous chapter, I argued that cultural ideologies of gender are intensely problematic for the medical profession. These ideologies are particularly important to the practice of contemporary gynecology. The experiences of trans men receiving this type of care provide an especially clear view of how these ideologies fall short in adhering to the tenets of both evidence-based medicine and patient-centered care that are foundational to modern medical practice.

The right body for gynecological care

According to Peter, the experience of being transgender is "predicated on having to jump through medical hoops," hoops that require trans men to "adhere to a binary representation of gender." Trans men are not the only patients required to jump through binary gender hoops in order to access medical care. The emergence of women's health, with an emphasis on preventive gynecological and breast cancer care, are bounded by assumptions about gendered bodies due in large part to the efforts of the Women's Health Movement.

The practice of contemporary gynecology was profoundly reshaped by the activism of the Women's Health Movement which advocated generally for women's empowerment in medical interactions and specifically for the rights of female patients to be knowledgeable about their reproductive organs and to be connected to their bodies during gynecological care. This activism also led to the widespread creation of women's health centers, a trend which opened space for

LGBT health centers as well. The impacts of the Women's Health Movement remain complicated with respect to transgender people. While the emphasis on women's identities and embodiment were critical to improving the experience of gynecological care, this activism categorically excludes those individuals who identify as men and yet may require gynecological services. The bodies and identities of transgender men are difficult for many providers to comprehend and the advice available to practitioners fails to encompass the range of embodied experiences of trans men.

The profession of gynecology is rooted in assumptions about women’s bodies and what it means to be feminine. These assumptions have evolved over time to reflect various socio-cultural shifts in what it means to be a woman in society. The Women's Health Movement of the 1970s represents a major turning point in popular understandings of health, the practice of medicine generally, and gynecological care specifically. Beginning in 1969, the women's health movement brought feminist concerns to health care and launched an ongoing process of altering medical interactions to shift more power and autonomy to the patient. The movement sought to challenge the authority, knowledge, and power of the masculinized medical profession in order to help women gain control over their own bodies. Women in the movement set up feminist and women's health centers, trained lay people in well-woman care (e.g. natural remedies for common illnesses such as yeast infections, Pap smears, cervical exams, etc.), advocated self-help health care (e.g. group meetings similar to consciousness raising sessions where women learned their anatomy, learned self-examination techniques, and other health related information), set up programs to improve gynecological training in medical schools, pressured state and federal government to legalize abortion, created shifts in the relationship between doctors and patients, and led to rising numbers of female physicians because activists argued that women were best treated by other women (see Morgen 2002 and Ruzek 1978).

Importantly, the Women's Health Movement brought to the mainstream a critique of the tendency within biomedicine to abstract the body from the person and made explicit the gendered and sexualized power dynamics within medical care. In Emerson's (1970) study of gynecology, she observes the ways in which physicians and patients manage a sexually charged exam by crafting specific roles for each which reinforce particular culturally gendered expectations (e.g. a passive female patient, comfortably detached from her body). Prior to the women's health movement, exams were conducted with a drape separating patient from physician and patient from herself. This act of draping served to reinforce power structures based on knowledge: physicians possessed the ability to see and thus to know the inner workings of a woman's body. The drape reinforced not only a woman's inability to see her reproductive organs but also served as a reminder that she ought not attempt to see or to know. This power hierarchy, based on vision and knowledge, also reproduced the ideal passive patient that physicians encountered in their medical training. Until relatively recently, gynecological training occurred on plastic models, anesthetized patients who may or may not have given consent, on cadavers, or on prostitutes (who reinforced the sexualized nature of the exam) (Kapsalis 1997; Morgen 2002; Ruzek 1978). Again, this training stressed a disconnection between the patient's self and her body as well as to privilege physicians as those who possess vision and therefore knowledge.

The emphasis on patient control over the terms of the exam and over his/ her own body *should* contribute to increased understanding of trans patients and the provision of supportive care, however the emphasis on woman-centered care contributed to a discourse that rendered gynecological screenings "a key entitlement which women could, and should, claim from the state [and] as an identity marker, as a mark of sisterhood" (Howson 1998, 198-199). Not only is gynecological care framed as a right, but it also serves to construct female bodies, sexualities, and women, thus reinforcing a normative gender structure (Kapsalis 1997).

It is possible, however, to exercise resistance in the face of medical pressure to conform one's body and behavior to ideologies of gender. Sociologist Natalie Armstrong (2007) specifically focuses on resistance in her study of cervical cancer screening. In the United Kingdom, universal healthcare has created a different political and cultural context for reproductive cancers and remains a fruitful site for exploring resistance to and affirmation of gender structures. Further, health care coverage for all individuals minimizes the urgency of access-focused studies and thus allows greater freedom for researchers to explore the relationship between gender structures and individual experiences. In the United Kingdom, women are "invited" to attend a screening. Armstrong argues that this invitation, in the form of a nationally produced leaflet and locally produced letter, represents the official national discourse on screening and draws on normative ideologies of femininity. Upon receiving the initiation, women adopt "a range of alternate subject positions" by which "women demonstrate an active and critical engagement with the official discourse on screening, problematize it, and raise important questions about how screening is presented and communicated to women" (2007, 69).

Armstrong uses interviews with women to argue that the official discourse fails to reflect the experiences of many women (2007, 71) and "to demonstrate how women can and do demonstrate forms of resistance to the official discourse that surrounds cervical screening" (2007, 72). Following from Foucault, she argues that practices of the self provide the means for resistance. Because the official discourse of cervical cancer screening draws on taken-for-granted norms of femininity and citizenship, women thus resist these norms in the practices of the self that they adopt upon receiving their invitation to screening.

Importantly for Armstrong, resistance is not equivalent to non-attendance at screenings. Most women had undergone several screenings in the past. The invitation to screening is an "ethical moment" in which "critical self-awareness or reflexivity" is achieved, and as such the space for individual resistance to official discourse is opened up (McNay 1994, 155 quoted in Armstrong 2007, 73). Resistance for Armstrong is not behavioral, but related to discourse and as such the narratives of women whose experiences differ from the official discourse provide opportunity for transformation. To this, I add that resistance can be rooted in interactions. When a patient (either a trans man or a cis woman) submits to the exam but does so in ways that challenge the normative assumptions at its foundation, the interaction necessarily shifts to deal with the situation. Acquiescing to the exam can be one of the first steps in overall resistance and structural change.

The activism of the Women's Health Movement has rendered gynecology as not only a right but also a rite of passage marking an individual as a woman. This transformation has shaped medical knowledge about women, femininity, and biology in a way that is especially problematic for transgender men who are not women yet have body parts that require this type of medical care. Patients and providers alike view gynecological care as woman specific, thus ostracizing transgender men. Bodies and identities become conflated in a way that can render gynecological care inaccessible or, at best, problematic for transgender men. Seeking gynecological care puts transgender men in conflict with a narrative that assumes they are uncomfortable with their reproductive organs and may dis-identify with them to the point of avoiding care.

Men in Women’s Health Care Space

A patient's first impression of a health care facility can contribute significantly to his comfort. A wide variety of medical specialties are skilled in providing basic gynecological services. Seeing an actual gynecologist is only necessary for major medical issues such as hysterectomies. While the exam may be routine, the experience leading up to the exam can differ based on the specialty of the provider. The differences include the name of the clinic (many gynecological clinics have "woman" or "women" in the name), the décor, the forms one must fill out before and appointment, and the color of the gowns. Joe described the logo of one clinic as a drawing of a "horrendous stick figure, lady, thing, with a really obviously pregnant belly and really prominent breasts." Pink gowns and flowery décor were also a sign to Joe that he did not belong in a particular clinic. "I recognized that I was going into an office that 99.99% of the time is used solely for cis women. I thought of it as enemy territory. … It helps to give yourself a little narrative, so I was going into enemy territory." While it is unclear if such a feminized atmosphere is particularly soothing to cis women, the first impression of an office can signify the degree to which a trans patient will be confronted with the “wrong body” narrative.

To avoid entering what he jokingly referred to as “enemy territory,” Joe only sought routine care at family medicine practices because he believes that "family practitioners have a much better warm view [sic] of trans people than internal medicine does. That's just the way I've always looked at it." Joe’s explanation of various clinical settings reflects what has come to be called the “therapeutic environment” in medical and cultural geography. The concept of the therapeutic environment encompasses “the physical, individual, social and cultural factors that come together in the healing process” (Williams 2002, 142). Everything about a clinical space from the colors on the wall to the actual architecture of the space “can impact upon social relations in ways that may be constitutive of them, in ways that may perpetuate dominant cultural discourses, and reinforce social divisions, inequalities, and exclusions" (Gillespie 2002, 211). Joe's humorous description of gynecological clinics as enemy territory highlights the ways in which the social space in which exams occur are influenced by normative ideologies of gender. The space of the clinic becomes a distinctly gendered zone, much like a bathroom or locker room, and thus open to gender policing to ensure that all bodies and behavior conform to expected gender norms.

Gynecological offices are not necessarily disconcerting for transgender patients. Erik uses a gynecological clinic for his care and had only positive statements about his provider. In contrast to Joe's description of an overly feminine office, the office where Erik obtains care is similar to a "hotel lobby… stylistically it's nice… everything looks kind of new. They try to make it so you have a conversation with your doctor and then you have an exam." There are two key differences in Erik's clinic and the generic gynecology office that Joe described. The first is a gender neutral, non-medical style. The other is the way that the interaction occurs within this neutral space. Erik described his first Pap smear at this current office and indicated with respect that his provider always used male pronouns. His comfort in the office was also encouraged by the behavior of front desk staff who validated his gender identity.

> Here is a guy sitting in your waiting room in the OB/GYN clinic, and we're talking about a receptionist, right? Not a medical provider, not a nurse, like not a doctor, not a nurse, this was a receptionist, and who knows what training this person has had, but the patient, who is a man, comes up, gives you the paperwork and says, I'm here to see XYZ doctor. They were never confused as to why I was there. They never looked at me funny. They always looked me in the eye, and they treated me like every other person, you know?

Jamie also spoke highly of his care providers. Jamie explained that this provider "checked in with me about pronouns" and consistently made an effort to create a comfortable atmosphere where his body and identity were unproblematic.

> I think, for me, the key was always feeling like my provider could understand that my gender was one thing but my body was what it was. The fact that my gender was masculine didn't mean that they could ignore the female parts of my body.

Several men felt that health care providers were able to respect both the identity and body of the patient in front of them. These statements affirm research findings that provider use of appropriate pronouns and names is very influential in establishing comfort and trust in medical care for trans patients (Hagen and Galupo 2014).

The key to a positive medical experience for Erik was being treated like he had a right to be in the office, not that he was a “wrong body.” Medical interactions were characterized by staff acknowledging a series of unspoken cues from Erik with the result that he felt like he was being treated as a unique individual. Additionally, he was never made to feel like his identity and body were medically at odds.

> I present very masculinely. I do this on purpose. I'm not unaware of the fact that I'm saying to the world like, I want you to look at me like a man, you know? And they responded to what I felt like I was communicating on an unspoken level, and they never challenged that. They never questioned it. They just responded to Erik. They responded to my whole person rather than being like, oh, you're a trans person, and these are a collection of symptoms, or problems, or concerns, or you must have this problem because you're trans, or you must have this concern because you're trans, or you must have this kind of anatomy. They never assumed what my genitalia was, which also meant a lot to me. … I got to live in a world where it was normal to be a guy with a vagina. Nobody was freaked out by that. Nobody had questions. Nobody didn't know how to treat me. … They treat me like a human. It's not weird or abnormal, or uncomfortable that I am a guy with a beard who has a vagina, you know?

Erik attributed his positive interactions with the medical profession center to trust and communication. Taking Erik's identity and body at face value were critical in establishing a trusting environment for care. In the passage above, Erik is speaking to the ways in which his medical providers were able to see his identity and his body as a unified whole, rather than as discordant and troubling.

Many men unfortunately had negative experiences with medical care generally and gynecological care specifically. Zach's explanation for avoiding gynecological care stemmed from generally uncomfortable situations within health care settings.

> I always looked like a guy and I just had a girl's name. And so whenever I was in the doctor's office and my name would be called it would be embarrassing for me to get up because people would be like oh, I thought that was a guy. And so now when I'm finally like okay, I have a name that finally matches the way I look, I'd rather not go back into a situation, like I did for 18 years of my life, where I get called and I have to get up and it's awkward.

The type of awkward situation described by Zach can be especially difficult during recovery after a hysterectomy. Upon check in patients are given identifying wrist bands with their name and occasionally a gender marker. After surgery, patients typically recover in a hospital room. Despite a very understanding surgeon, Chris experienced conflicts with the hospital staff at large.

> The thing that I always say upset me the most was [the nurses] came over with the wristband and it says the letter "F" on it. I was like, can we switch that to an "M" or anything? I mean I know that you need to have a number on it, but I can write in Sharpie on it, "M." The hospital gave me a bunch of bullshit reasons. The first one they gave me was, when you get on the operating table, your surgeon's gonna look at the number and if it says "M" she's not gonna know who you are. I was like, that's bullshit. Absolute bullshit. … One of the other reasons that they gave me was that I was female because I had ovaries and what have you. I was like that is also extremely rude. Do you know how many women have to have a hysterectomy for one reason or another? Are you telling me that they're not female anymore?

Gabe also described the difficulty presented by post-hysterectomy hospital stays. He described for me the experience of a friend who was placed in a shared room with a cisgender woman after surgery: "That patient had his mother and his fiancé in that room while he was called the wrong name, the wrong pronoun." For Gabe this inability to use appropriate names and pronouns creates a disconnection between the patient and the healing process. Ultimately, Gabe felt that medical interactions were deeply confrontational because he believed that trans identities and bodies are not properly respected in medical care.

> All things being equal, you can have nine women come in and there's some kind of understanding and appreciation that you're helping me to stay healthy. From a transgender patient [perspective] you're not. There's an anxiety and a pain level and a discomfort level walking in. There's a tension to the body and it's resistant to the care that's being offered I would suggest to you and so that's gonna present in the exam. It will be more difficult to do what you do and know that we're fighting you [laughs] at least I am. I'm fighting whatever you do. and here's the thing about that, that's why we don't go to the doctor. I'm gonna speak because I've heard these voices, alright, and most of us would rather *die* than to be treated for that kind of care like gynecological or mammograms. We won't go for those exams. We'd rather die.

While Gabe's sentiment is more extreme than those expressed by most of the men in this study, the sense of concern about how one's identity and body will be perceived by the provider was common. Using the right pronouns, the right name, and accepting both the body and identity as they are presented are determine for some trans men whether a medical experience is ultimately positive or negative.

The bodies of trans men are thus not only wrong for gynecological care, but also become "savage bodies" within gynecological care (Sault 1994). Rendering trans bodies as savage marks trans men as "other," creates opposition between their bodies and their sense of self, and "reduces the other to a specific body part that holds special meaning for the observer" (Sault 1994: 6). Peter theorized trans bodies as "radical bodies" and believed that medical discourse needed to account for these bodies instead of what, in his experience amounted to "alienat[ing] or push[ing] away" these radical bodies. Peter here is arguing for the redoing of gender through medical interactions. As radical rather than savage bodies, Peter suggests that gendered expectations of bodies and behaviors can expand to incorporate more fluid connections between body parts and identities. The bodies of trans men in the context of gynecological can also be understood as resistant bodies; bodies shaped by a series of choices that do not necessarily conform to normative ideologies of gendered bodies.

The right body for gynecological care

All of the men in this study had engaged in some form of medical intervention to alter their physical bodies. These interventions can include any combination of hormone therapy with testosterone, top surgery (i.e. bilateral mastectomy), and bottom surgery (i.e. altering genitals via phalloplasty or metoidioplasty as well as reproductive organs via hysterectomy and/or oopherectomy). 12 men in this study had top surgery, 12 were on testosterone, five had undergone hysterectomy (three were considering it), and one had a scheduled phalloplasty (see Table A.1). At the time of the interview, all respondents expressed a general sense of comfort with their bodies. While some wanted to eventually alter their bodies through bilateral mastectomy or phalloplasty given adequate financial resources, the men who took part in this study had reached a point in their lives where their bodies were not discordant with their identities.

Gynecological care, however, brought the integration of body and identity into question for some men. Erik spoke passionately about the ways in which reproductive organs are laden with meanings about sex, sexuality, and gender.

> When it comes to something like gynecological care, we're talking about parts of people's bodies that are highly sexual. I mean, they're all kinds of things, right? They're highly arousable. They're highly sexual. They're highly sexualized. They're highly gendered.

For Erik, gynecological care is a "violent act" because, in his experience, these exams detach a patient's body from his identity as a man because the body involved in gynecological care is necessarily female.

Joe's reasons for generally avoiding gynecological care derived from the connection between gynecology and femininity.

> The exterior genitalia is [sic] very much associated with a gender I am not. I don't want anyone to judge my gender based on my genitalia. While I feel pretty secure in my gender, I think there is always that nagging voice from my head from when I was a kid, from when I was judged incorrectly on my gender based on my external features… there's a large part of me that's very much afraid that I would still be judged female by someone looking at my genitalia.

In everyday life, however, Joe did not see his genitals as a source of anxiety.

> I'm not a trans guy who feels like he needs a penis. I don't need a penis. … I don't feel any sort of connection with the thought of having a penis. On the other hand, … the uterus and the ovaries don't bug me either. They're inside and I really don't care about them other than I would prefer they not give me cancer and kill me.

The overt attention to "purportedly gendered body parts" (Spade 2011) in gynecology links the body (internal reproductive organs and external genitalia) to a particular social category (female). As Joe indicates, his personal comfort with his body and identity are questionable within gynecological interactions. In this moment, Joe's body becomes a site of struggle between his identity, the institutional discourse of gynecology, and cultural norms of femininity. Gynecological exams represent "a threat to the organization of the embodied self" (Waskul and Vannini 2006: 13).

For Zach, as long as the reproductive organs remain invisible and don't cause a major health issue, they can be ignored. Zach's ability to ignore his genitals was central to his avoidance of gynecological care.

> Some trans people are kind of at peace with maybe just like getting the top surgery and just sort of leaving the bottom as what it is. I don't have the kind of money to fix it and I usually just ignore that part of my body. Obviously I have to acknowledge it's part of my body but I don't even give it a lot of thought.

Gynecological exams force trans men to consider both the internal and external reproductive organs. When trans men submit themselves to gynecological care, they can experience body betrayal that is characterized by feeling "simultaneously disembodied and acutely aware of their bodies" (Rubin 2003, 95). The experience of gynecological care is akin to that of puberty when the bodies of trans men begin to change in ways that delegitimize their identity. Rubin notes that trans men rely on a discourse of body dysmorphia, characterized by discord between their body image and their material body, to become "treatable bodies" (2003: 94). In so doing, medical interventions like surgery and hormone therapy are rendered appropriate treatments. When trans men seek gynecological care, they become potentially untreatable because the uterus and ovaries (as well as their function and care) are central to the definition of womanhood. When trans men present at the doctor's office for gynecological care, be it routine or emergency, their bodies can become untreatable because of the gendered assumptions built into such forms of medical treatment.

Several trans men in this study worried that their bodies and identities would be called into question upon entering the exam room. As Chris puts it, "[health care providers] go, 'Oh, you have this symptom, therefore you must be that [i.e. an internal reproductive symptom, thus must be female] instead of being trans *people*. Really, you are trans first, you're not actually *people*." In this way trans men are a medical anomaly when seeking gynecological care by being made distinct from cis women in these exams. Cis women get to be "people" because the relationship between their body, their identity, and medical care make sense to providers. In the language of West and Zimmerman, cis women exhibit accountability to gender norms. A transgender identity can thus induce an instinctive and subconscious complication for providers because these norms are taken for granted, making what could be a routine procedure into a problematic event.

The sense that gynecological care creates tension between body, identity, and medicine leads some men to expect an uncomfortable experience. When I asked Zach if he had ever had a pelvic exam, he replied, "Absolutely not. (laughs) It's just something that I'm not comfortable with at all." Isaac explained the source of discomfort as stemming from provider expectations about the body they will treat.

> What I'm afraid of is when people are surprised by the fact that my body is not what they expect, that it literally like, shuts down their ability to process information in their brain (laughs). Like, it becomes something that's totally all-consuming I don't know if this is actually what's happening. I'm just postulating. But like, their ability to then ask relevant medical questions, to provide me with information that's necessary, to communicate with other medical staff at a level where they were previously before finding out that I was trans. It just goes down. So, I think that because it's such a surprise to people it hinders their ability to function as medical professionals. And so my fear is I'm going to go in, they're going to get freaked out, and then they just won't be able to do their jobs in the way that I absolutely need them to do their jobs. So, that's what my fear is.

Like Isaac, Peter worries about the ways providers respond to his body. To avoid misunderstanding, Peter takes on much of the responsibility as a patient in ensuring that his body is treated with respect and without assumptions:

> The way that I talk about my body [in health care], it's all about accuracy. … I use the word "vagina" to describe my genitalia. I'm very comfortable doing that. I think before I transitioned it was just a part of my body that I just didn't want to deal with, and so I didn't.

While Peter has become comfortable with this language, many other trans man would not use the term "vagina" to refer to their genitals. Regardless of terminology, Peter's advice to health care providers is clear, "if your aim is to provide care, it should be your goal to do everything in your power not to alienate or push that body away." Making assumptions about the body or using the wrong body narrative to understand all transgender patients has the effect of simultaneously alienating the body and the identity of the patient.

The decision to seek care

Despite the possibility of uncomfortable interactions, many trans men chose to obtain preventive gynecological care. Men in this study reported a number of reasons for seeking such care, including a family history of gynecological cancers; acute medical issues, including concerns about sexually transmitted infections (STIs); and a commitment to personal health and/or health activism. Often men explained that a combination of these factors motivated them to make appointments for gynecological care.

Family history

Joe and Isaac both had family histories of gynecological issues including cancer. Joe had studiously avoided gynecological care until his wife encouraged him to have a routine screening after she learned about his family history of endometriosis and cancer. Joe was not enthusiastic about the gynecological exam but submitted to this, his first exam, to appease his spouse. He had avoided this care because his concerns about the exam trumped his fear of cancer.

> The risk of cancer is a very theoretical thing in the future. It's something that wasn't staring me in the face. Thankfully I don't have a massive tumor growing inside of me that I can feel and palpate and otherwise interact with, so the risk of cancer is something very theoretical. The act of going to a gynecologist and having instruments put places where I don't put anything was a very real fear. It was much more real than the risk of cancer to me. It was easy for me to face the thought of cancer because I could simply choose to ignore that [but I couldn't ignore] the risk of going to a care provider and having them do things to me that I did not want, that weren't going to be ok for me as a trans man.

As a result of Joe's history and discomfort with the exam, a hysterectomy ("hysto") was offered as a medically viable solution. Unfortunately for Joe, this requires at least one more gynecological exam.

> I know I'm gonna have to get a manual exam [sighs]. I'm not happy about that, but if it means that I can get a hysto and then never have to worry about them again, I guess that's a negative I'm willing to endure in order for the positive of not getting uterine cancer or having that risk any further and never having to undergo another physical exam again.

Gynecological care, specifically a hysterectomy, is for Joe a reasonable option for alleviating future medical risks and will eventually allow Joe to ignore a part of his body that can create discord with his identity.

Isaac also chose to engage in regular gynecological care because of his family history. He eventually came under the care of a physician who recommended hysterectomy given his medical history and identity as a trans man.

> I had had ovarian cysts. I come from a family of endometriosis and my mom had also had pre-cancerous tumors in her uterus where she had a hysterectomy when she was really young. So, I have a ton of indicators that it wasn't a 100% healthy uterus and/or that it would be very easy to advocate for the removal of it.

While Isaac was not particularly troubled by gynecological exams, he was happy to be free of this type of medical care. His interactions with the medical community for non-transgender related care were frustrating for him and he felt that it was a relief to have one less medical interaction to manage.

The experiences of Joe and Isaac suggest that gynecological care can serve three purposes for trans men who have a family history of gynecological cancers and other health issues. The first is to detect problems early via regular exams. Second is the use of gynecological surgery as a preventive measure to avoid future risks. Finally, gynecological surgery and the exam that provides access to it can remove body parts that necessitate such care. The decision to pursue a hysterectomy effectively removes trans men from the cycle of gynecological cancer care. Rather than trying to change medicine to accommodate their bodies and identities, these trans men change themselves.

Acute medical issues

Some men avoid gynecological care until something is obviously wrong. Chris, for example, experienced intense pain in his abdomen and was repeatedly told by his primary care physician that nothing was wrong. After four months of pain with no real response from his physician, Chris ended up in the emergency room. The nurse practitioner he saw there referred him to a gynecologist for follow up. I spoke with Chris a few weeks after his hysterectomy.

> I had the hysterectomy in October. [Earlier that year] in February, I was feeling pain sort of in my lower abdomen, pelvic area I had gone to see my doctor and after four times of him telling me that I'm just having gas and making it up. He said there was nothing wrong, there was no pain and that I needed to stop coming in for that reason. … Then in early June, I was in the ER because the pain was so severe. I was supposed to follow up with my doctor, but he was out of town for three weeks, so I ended up seeing a nurse practitioner. She said, this is a real problem. I'm gonna get you in to see a specialist because I don't know how to handle this. … so I saw the specialist in August, late August, and she did a full pelvic exam and said the good news is, you're not making it up. The bad news is, I can feel something, and then asked me if I was later in life thinking about getting a hysterectomy at any point.

Although Chris did receive routine gynecological screenings, the acute issue of pain was a particular catalyst for obtaining gynecological care and ultimately a hysterectomy. This was a welcome surgery for Chris because he was thus able to opt out of future gynecological care.

No stranger to gynecological care, Peter ended up in the emergency room concerned that he might have an STI after his "vagina was pouring out rivers of unidentified fluids."

> I didn’t even make an appointment I just showed up and I was like there is stuff pouring out of my vagina, which is hilarious because I have a beard, you know? So, I go in and the stuff is pouring out of my vagina, I need some help. The person that I meet with is like I hear you. That is terrible. I also have a vagina. So, we’re on the same page. We’re like, going to deal with it. [And she tells me the] treatment options: you can have a cream that you shoot up into your vagina. You do it at night and it’s kind of going to leak out, you might want to wear a panty-liner. And I'm thinking: in my boxer shorts? How? No. [And the other option is] you could take a pill that will also kill off other good flora and fauna in your system. So, I tell her I'll take the pills. And she says, Really? I’m shocked. That’s what she said. I’m shocked. I said, are you? Tell me about that. She said well, were I making this choice for myself, I would totally go with the localized treatment because I know that it would treat only the bad stuff and it would be

> over in a week. And I said I totally hear you but I’m trying to make the things stop pouring out of my body. I don’t want to introduce more things that are going to come out and I think it’s hilarious that you would suggest a panty-liner to me.

For Peter, his identity as a man and the fact that he has a vagina are not irreconcilable facts. Yet, his health care provider had trouble incorporating Peter's identity into her idea of appropriate care in the situation. Often providers do not intend to cause harm or discomfort for their patients. In the example of Peter's nurse, she was genuinely puzzled by his resistance to local treatment. Her confusion reflects the taken for granted assumption in medicine that gynecological patients share a common experience as women. Culturally and medically, gender is a binary system. Encountering a patient who troubles a binary understanding of gender or the relationship between bodies and gender identities requires the provider to undo a lifetime of exposure to cultural norms about femininity, masculinity, and the bodies associated with each.

The experiences of Chris and Peter are indicative of the types of acute problems that may drive trans men to seek gynecological care. Pain, unusual discharge, and other physical symptoms make it impossible for men to ignore body parts that might otherwise garner little attention. In these situations, trans men may be acutely aware of the incongruence between their bodies, identity, and medical care yet are compelled to seek this care because the risks of avoiding it have become immediate, rather than far in the future as they were for Joe.

Sexual health

Sexual health was another reason given for pursuing gynecological care. Prior to 2009, initiation of sexual activity was one of the standard indications for beginning gynecological care (Snowden 2009). As an endurance athlete and nursing student, Erik recognized the importance of routine health care but believed that his concern for gynecological health increased after his transition.

> I've had a lot more gynecological care since I transitioned than I ever did before I transitioned. Mostly because I had a hysterectomy. Also, having insertive or receptive vaginal sex, I'd been concerned about STDs, so I've had vaginal exams, and STD testing within the context of a GYN office. My experiences before that … they're very vague memories that I have, and to be honest, I think that I became more aware of my health needs gynecologically after I transitioned. I would get recommended to have a routine Pap smear done by like a primary care provider, and I would get in these highly theoretical arguments with them about the fact that like I wasn't having receptive vaginal sex, and I didn't really think that was necessary, and at a certain point, I think I needed a physical, and I finally had a Pap smear. … After I transitioned, though, I became a lot more active about gynecological care for a number of reasons. I mean, I identify as a gay man, and I have receptive vaginal sex with men who have penises, and I was very aware of the fact that I had risk for STDs. I became really aware that it was necessary for me to have Pap smears done. Now that I'm thinking about it, I don't think I had a Pap smear done until I was always on hormones. So I would've been like 23. That's probably later than a lot of people have Paps done. I remember afterward thinking, oh that really wasn't that big of a deal. … I don't remember feeling emotionally vulnerable. I remember he used male pronouns the whole time.

The sexual concerns discussed by Erik are another reason men in this study gave for pursuing gynecological care. A year prior to his hysterectomy, Chris had his first pelvic exam because "I'm having sex, I should probably do some sort of pelvic exam to make sure I'm having safer sex and anything I have I don't want anyone to get."

A commitment to health can also emerge from a professional and/or activist identity. Five participants had or were in training for professional careers related to health care. Three men were involved in health care activism, advocacy, or volunteerism. Others discussed a general understanding that routine physical exams, including gynecological screenings, were simply the appropriate way to ensure health. For Jamie, a concern for health had been a constant part of his identity.

> My mom worked at [a major metropolitan medical center]. … When I was in high school I was really involved in doing safer sex education with an LGBT health center, so I think I kind of grew up in this queer health arena that's kind of unique. I grew up in this environment where gynecological care [for queer people] was normalized.

Peter's parents were also medical professionals and he spent a lot of time with his parents at work, either after school or because they'd been called in during the night. Peter's comfort with hospitals and medical care generally along with a growing feminist consciousness inspired him to participate in an early study for the HPV vaccine. In explaining his participation, Peter spoke at length about his commitment to women's health and the encouragement of his mother.

> I think [the research team] put out a call. I can't remember if it was in the paper. My experience with the medical industry has always been personal because both of my parents work in the medical industry. So, in the first place, I'm predisposed to participation. I over-participate. Probably my mom told me about it, or I read about it in the newspaper. It was probably a combination of those things. They were just looking for women's bodies and I happened to have a cunt and I happened to be a budding feminist, and I had a lot of Ani DiFranco on my mind. It was before I even had the language to flesh out what I was doing with my body, I was just interested in participating in a medical study that had to do with the benefit of other cunted creatures, and women's bodies. I knew I cared about women's healthcare. I was also like, super pro-choice, and I was already engaged and thinking through the politics that play out on women's bodies, and extend that to say that those wars are waged not only on women's bodies, but also bodies of diversity. It was in line with my budding politics.

Peter's memories of participating in the HPV research study situates him squarely in the tradition of women's health activism begun in the 1970s. Although he is now highly critical of the "medical industrial complex," Peter still sees his voluntary participation in routine exams as part of his commitment to contributing to medical knowledge and to encouraging diverse groups of people to be informed consumers of medical care. "I've done a lot of direct activism in small ways in healthcare because I think we must radically reconfigure the way that we have agency over our own bodies." Again, Peter's activism around health care is embedded within the discourse of the Women's Health Movement. Health care is both a right and an obligation. In Peter's estimation people with "bodies of diversity" remain in a precarious position with respect to health care and he makes an effort to improve this position. Peter is an example of the effects of feminist health activism, yet he is unimaginable to this variant of feminism. As such, he embodies the very problem of gynecology and women's health care more generally. This care is based on a particular relationship between patient gender identity and patient body. While the difficulties associated with these assumptions are particularly troubling for trans men, they are relevant to cisgender female patients who fail to live up to these normative standards as well.

Managing clinical interactions

Once trans men decide to pursue gynecological care for any of the reasons discussed above, they then are faced with the exam itself. These experiences vary widely. Some men reported fairly positive experiences with understanding providers while others recounted much more painful ones. Often the positive experiences occurred in the setting of primary care where individuals had identified a particularly supportive provider. The more negative experiences often occurred in emergency settings or in interactions with medical staff who did not have an established relationship with the patient. Trans men reported two key approaches to managing the exam: dissociation from one's body and/or the exam and becoming very assertive so as to set the tone of the interaction at the outset of the exam.

Dissociation

Gynecological care can be deeply distressing for some trans men. Several trans men described their strategies for dissociating in order to cope with the exam. In some cases, dissociation was a way to disconnect one's identity from a sense of incongruence with one's body that is magnified in health care settings. Gabe began dissociating from his body early in life.

> It's all part of my out of body experience. It was just part of my very awful experience of having to be out of body every time anyone treated me. Whether I had a mammogram, whether I had a Pap, or whatever it was it was a violation. It was a rape on some psychic level for me, so I had to go out of body and just let them treat the body and I was not connected to it at all. … I just went somewhere else because it's invasive and it's a violation for me personally to have inspection

> in those places, of things that I don't relate to that aren't part of me in my persona and my understanding of myself.

For Gabe, medical care magnified his discomfort with his body because while the body may be an important factor in everyday interactions, it is the entire focus of medical interactions.

Several men expressed a general degree of comfort with the bodies until faced with gynecological exams. In these immediate situations, some men like Joe, dissociate from the exam through the use of anti-anxiety medications and/or by having a social support present for the exam.

> I'm just glad they let [my spouse] be there and let me kind of retreat into my own mind. I remember specifically saying, 'I'm checking out. See you guys later.' Letting the Ativan take over and just kind of not being present for it. [The doctor] did a great job explaining to me what she was going to do but she didn't expect me to talk or interact. She seemed to know that I was gonna wall off in my own little protective fort in my mind and just try to disassociate as much as possible. That might not sound like so much that she allowed me to do that, but that was huge.

Joe's doctor and nurses also found him "a non-pink gown" and allowed Joe's spouse to "be right in the room, holding my hand." Joe knew that disassociation would be his primary strategy for managing the exam and his provider made an extra effort to improve his comfort by diminishing the feminine overtones of the exam and encouraging the inclusion of Joe's spouse. Joe’s experience is somewhat unique in that his spouse is a physician and used her medical connections to ensure that the more feminine aspects of the exam were downplayed.

Like Joe, Chris relied on the support of friends and a prescription for Valium to deal with gynecological care. " One of the nurse practitioners I felt really comfortable with [gave me] a high prescription of Valium and I had two friends that were in the room with me." In order to endure follow up exams leading up to a hysterectomy, Chris needed a high dose of Ativan to render him unconscious. The switch from Valium to Ativan was due to unpleasant side effects of the former drug. Both Chris and Joe describe Ativan as taking them to a "happy place" during the exam. In addition to the social support of friends, Chris utilized a service dog to help manage his anxiety. Prior to his hysterectomy Chris' surgeon encouraged him to visit the office to see the waiting room and an exam room, acknowledged that his service dog could be present during exams, and called several times to offer additional support and ensure that they were doing everything necessary to alleviate his anxiety prior to surgery.

Although dissociation was a useful strategy for some trans men in coping with gynecological exams, some practitioners see this as something physicians should work to prevent. In an article written to provide clinical guidance to practitioners treating patients with histories of sexual trauma, Dr. Pamela Dole writes that "it is important to help [the patient] in remaining relaxed and preventing disassociation" (2001, no page number). The assumption that dissociation is problematic has roots, in part, in the changes to gynecological exams promoted by the Women's Health Movement. While gynecologists might understand bodily dissociation as problematic, participants in this research explained that such dissociation is a reasonable way for transgender men to manage the exam.

For Kevin dissociation was a defensive strategy for managing an unwanted breast exam during a gynecological appointment.

> I've always had really bad dysphoria around my chest. And not getting her to do a chest exam was always really hard. And, even after explaining to her that I was trans and this was something that made me feel really uncomfortable, and that I wasn't okay with, and I'll take care of it on my own, thanks very much! The last time I saw her she ended up completely disregarding me and just went and did it without obtaining consent. And I started disassociating and I had like, flashbacks for like three days after, which has made me not very keen to go back.

Kevin's dissociation begins by using "chest" instead of "breast." Many trans men, like the cisgender men discussed in the following chapter, understand that part of their bodies as a chest rather than breasts. As Kevin points out, it can be extremely difficult to submit to a screening that is called a "breast exam" when you view yourself as having a chest. Because Kevin did not identify with naming that part of his body as breasts, the exam was felt to be an intrusive or violent. His only way to cope after clearly explaining that he did not want that exam was to detach himself mentally from the experience. Where Joe and Chris detached from the experience of the exam with intent and the assistance of pharmaceuticals, Kevin did so in response to an experience of stress.

Although the prevailing medical stance is against dissociation, the recommendation from physicians that trans men consider hysterectomies if gynecological exams are too distressing is actually a medically sanctioned form of somatic dissociation via surgical interventions. This surgery can be part of a strategy to avoid future medical risks (particularly cancer), yet removing organs from the body are also a response to dissociation or dis-identification as well as a permanent form of dissociation. Five men in this study had hysterectomies. Three men had hysterectomies prior to their medical and social transition and two had the surgery after. Additionally, three men were seriously considering the surgery. Kevin explained that a hysterectomy was the answer to his concerns about insurance coverage for gynecological care and the actual exam itself.

> It’s always a challenge, too, to know what to do with insurance and healthcare, and changing my gender marker or not changing it, and what does that mean for healthcare? And if my gender marker gets changed are they going to be even less friendly towards me if I need any kind of care, which is also influencing my own thoughts and decision making around whether I want to get a hysterectomy. Because it’s like, if I keep these things, which I don’t plan to do anything with them, not only will I have to keep going to see somebody every year or whatever, there’s also a possibility that something could happen cancer-wise. And then, like, hell, forget that. I’ll be seeing people all the time and they’ll be looking at stuff that I’m really not okay with.

Hysterectomies can be welcome options for trans men because submitting to gynecological care can be a fraught experience. Even when a man is comfortable with gynecological care it can be presented as an easy “solution” to the assumed problem of gynecological care for trans men. Isaac had regularly received preventive gynecological care throughout his adult life. He was fortunate enough to find providers who were comfortable with both his identity and his body. As mentioned earlier in this chapter, gynecological care was important to Isaac because of his family history of endometriosis and gynecological cancers. Even though Isaac was comfortable with gynecological care, he eventually agreed to a hysterectomy after his gynecologist assured him that the surgery would be “an easy sell” to his insurance company because he was listed with the company as a transgender male and because he had a family history.

Chris did not have as positive an outlook on gynecological care as Isaac. Chris sought medical attention repeatedly due to pain in his abdomen. After being told several times by his primary care physician that nothing was wrong, he eventually was referred to a gynecologist who told him " the good news is, you're not making it up. … And then asked me if I was later in life thinking about getting a hysterectomy at any point and recommended [a hysterectomy] because she had no idea what was going on." Chris' surgeon recommended a hysterectomy because he was in pain and she couldn't figure out the exact cause.

Hysterectomies are the second most common surgery performed on individuals with internal reproductive organs (Temkin and Koh 2014). The recommendation that trans men have hysterectomies if gynecological exams are uncomfortable represents a medical double standard. For a physician to recommend a hysterectomy for a cisgender woman, there must be a clear finding upon evaluation. This could be fibroids, endometriosis (not family history, but physical evidence of the condition), pelvic support problems, abnormal uterine bleeding, chronic pelvic pain (plus additional tests to ensure that hysterectomy is the best clinical decision), or gynecological cancer. Physical and emotional discomfort during gynecological exams is also not unique to trans men. Many cisgender women are anxious during these exams, yet no matter how anxious a cis woman may be, the surgical removal of organs is not seen by physicians as a medically appropriate alternative.

The ease with which trans men are presented with the option of a hysterectomy by medical providers is deeply embedded in cultural ideologies of gender. When women are faced with hysterectomies, they are confronted with what the surgery will mean for their femininity (see Elson 2004; Hallowell and Lawton 2002). According to Elson, women who had hysterectomies found themselves in a liminal state between woman and not-woman as a result of the removal of these uniquely female organs. Often, the removal of these organs and resultant unsettling of gender identity occurred simultaneously with a loss of trust in medical authority. Gender identity is tied up in a struggle for bodily control between medical practitioners and patients particularly when it comes to female reproductive organs. In their study of hysterectomy, Hallowell and Lawton found that women who have hysterectomies frequently expressed fears of physical masculinization (body changes, growth of facial hair, balding, deepening of voice) even though such an outcome is not scientifically supported (2002, 433). Women, in other words, didn't mourn lost femininity. Instead they feared impending masculinization but felt that controlling future risk far outweighed other concerns. The accounts presented by Hallowell and Lawton could suggest resistance to dominant narratives of femininity and cancer. Women with high risk for ovarian cancer did not necessarily fear a loss of femininity (the dominant discourse used to explain the experience of gender-specific cancers). Instead, they feared gaining masculinity. This logic is precisely what underlies the medical recommendation to offer hysterectomy to trans patients under circumstances that would not otherwise apply to cisgender women. Hysterectomy is culturally understood as a surgery that disrupts femininity. Even though this is not a scientific fact, i.e. not evidence-based medicine. This cultural logic permeates the medical experiences of trans men.

The medical standard suggesting trans men and their providers consider hysterectomy may seem self-explanatory until one considers that this is not an option for cis women. If these are merely body parts, then the identity of the patient should be irrelevant to clinical decision-making. That is, in terms of evidence-based medicine, either there is a scientific rationale for the surgery or not. If considering the principle of patient-centered care, then cis-women should also have the option of a hysterectomy. One complicating factor here is the role of hormones. Although not explicit, the recommendation that trans men undergo hysterectomies presupposes that these men are being treated with the hormone testosterone as part of their transition process. One of the key functions of the ovaries, aside from producing egg cells for procreation, is to produce the hormone estrogen. Removing these organs generally requires external hormone supplementation. For cis women this would be estrogen replacement therapy, while for trans men this would be testosterone. Estrogen replacement therapy for women, particularly pre-menopausal women is not medically advised. The use of testosterone by trans men has been accepted by the medical profession, thus rendering hysterectomies unproblematic.

The matter of hormones reinforces the point that the removal of currently healthy ovaries and uteri from trans men is unproblematic *because they are men*. Removing organs associated with women's bodies and femininity will presumably bring the bodies of trans men more in alignment with their identities. However, the men I interviewed largely explained that these reproductive organs were inconsequential to their gender identities, thus conflicting with the underlying assumption that these organs have a greater gendered meaning.

It's important to recognize that transgender men have very different understandings of their reproductive organs. Some, like Kevin and Joe, are happy to be rid of their internal reproductive organs regardless of whether they desire any surgical alteration of their external genitalia. Others, like Noah, may be interested in becoming pregnant, a desire which Noah felt that the gynecologists he had seen found hard to understand. He stated that his questions about pregnancy and his potential for breast feeding "definitely cause confusion and providers either don't follow up or there's like this real weird curiosity." Noah also told me that, "No one really know what to do with most of my questions. People are definitely confused and it doesn’t line up with the storyline of what they think a trans guy should want or do."

When it comes to gynecological care, trans men occupy a difficult position. Providers and patients may expect and many experience discomfort in care. Dissociating is one possible strategy for managing discomfort. The stress of the exam produced dissociative outcomes from unconscious to intentional compartmentalization. Further, dissociation is connected to medical recommendations that trans men have hysterectomies rather than experience gynecological care. Underlying this stress is not necessarily discrimination or prejudice. Rather it is a sense that gynecological care is the province of women. To be a man or to treat a man in this context is unthinkable and so trans patients and the medical profession must cope find strategies for managing this interactional crisis. While dissociating with parts of the body and/or the exam in its entirety was one approach, another oft employed strategy was to embrace the role of the bio-citizen through assertiveness; making one’s needs and desires as a patient clear to health care providers.

Assertiveness

The trans men in this study also took on projects of educating medical providers during the evaluative process, largely by setting clear expectations with providers. As I mentioned earlier, Peter is very upfront with his providers about the terminology he uses regarding his body thus opening lines of communication. Chris is also assertive in his dealings with physicians.

> There's a lot of things when it comes to doctor's offices that I pretty much refuse to participate in. Part of that is that unless you are examining my body I'm not going to sit on the table. Early on when I see new providers and they say sit on the table I'm like, no I don't do that. Usually it's an "Oh, o.k., don't worry about it. When I'm doing the exam can you hop up on the table?" So that's been usually pretty good. Again seeing somebody new for the first time is always an I don't do this, I don't do that, this is not a thing that I do. But once it's out there it's oh, ok, whatever. I've been bringing friends less because I have a service dog so I feel a little bit more able to stand up for myself in a sense.

Noah also took an assertive stance in his attempts to obtain supportive gynecological care. Due to changes in insurance, he had to switch his provider numerous times. Each time, he called ahead to offices to try to find someone who specializes in or expresses comfort working with queer and transgender patients but has largely been unsuccessful. To address his fears about provider lack of knowledge about trans patients, Noah provides educational materials and, like Chris, sets clear boundaries for what's acceptable during the office visit. As he described his most recent gynecological visit with a new provider (two years prior to our interview), it became clear that his education forward approach has limited use.

> I brought with me some educational papers about trans bodies and trans health care. I try to initiate conversation so that I feel like I have a little bit more control and can also just get some things out of the way and have them be on my terms as opposed to weeding through inappropriate questions. So I just told the provider that I was here for OB/GYN care, for a screening, Pap smear and that I am transgender and I use pronouns he and she but prefer neutral language when it comes to my body and then that they limit the questions to what's relevant for the care today. And that I had some information, but if they wanted to do any further research on trans stuff, that would be great but not to ask through me. But I think I kind of – it shocks most people that I start (laughs) the visit that way. … [The

> doctor] didn’t have much to say but showed a little bit of surprise in my approach and then I – they left the room, I undressed and put a gown on. They came back in and proceeded to do the exam and while they were doing the procedure of the Pap smear, continued to talk about how interesting hair growth patterns were on my body which was really inappropriate. … I remember feeling like I'm prepared for this, but I didn't feel like I was able to say much while that was going on. So I just asked them to hold conversation until after the procedure was finished or the screening was finished and I wasn’t actually able to say how I was feeling until after I had my clothes back on and they had left and then come back into the room and I just said that I didn’t appreciate the conversation and had tried to ask for what I needed in the beginning and didn’t feel like it was respected and that like I said, if they wanted to learn more about transgender health care, hormone, surgeries, that there’s plenty of resources but not to ask that of their patients, especially during intimate exams (laughs). But I felt pretty choked up at that point so I didn’t feel like it was like my finest moment, but also I don’t feel like I should have to perform while receiving care. And I – I haven’t gone back since then.

Noah’s experience shows the limits of an assertive strategy for managing one’s health care. The burden of education should not fall on the patient. Additionally, cultural competency can serve as camouflage for providers asking inappropriate questions during an exam. The line of questioning that Noah describes is indicative of the overarching cisgenderism that pervades medical care. Cisgenderism "refers to the cultural and systemic ideology that denies, denigrates, or pathologizes self-identified gender identities that do not align with assigned gender at birth" and may be exhibited through a general ignorance of transgender people along with fear of or disgust about transgender bodies (Lennon and Mistler 2014, 63). When Noah’s doctor commented on his hair patterns, the physician was engaging in the process of establishing whether Noah’s body was right or wrong not only for gynecological but also for his gender identity. This is symptomatic of processes of legitimation that occur within medical interactions.

Discussion

The experiences of trans men who seek gynecological care and the medical standards of care for these patients indicate a constant negotiation of personal choice (the rhetoric of neoliberal paradigms of health and biocitizenship), accountability to norms of healthfulness and gender, and justifiable medical risk (itself a balance between risk of cancer and risk of complications from surgery). At stake in these negotiations is what various choices mean for my identity as a patient and how other people (including health care providers) see me. While these choices are not entirely shaped by gender, these ideologies are a significant and often unacknowledged launching point for patient/ provider discussions of medical options. The experiences of trans men with gynecology raise the issue of autonomy in medical care, particularly given the growing importance of patient-centered care. Butler argues that "choosing one's own body invariably means navigating among norms that are laid out in advance and prior to one's choice or are being articulated in concert by other minority agents. Indeed, individuals rely on institutions of social support in order to exercise self-determination with respect to what body and what gender to have and maintain, so that self-determination becomes a plausible concept only in the context of a social world that supports and enables that exercise of agency" (2004, 7). While these decisions are respected in certain medical contexts, namely those that can use the narrative of the wrong body to make sense of trans patients, in others trans bodies become invisible and/or troubling.

Trans bodies are rendered unintelligible for gynecological providers because the relationship between their body, their identity, and the gender-based assumptions of medical care don't make sense to providers in this context. In the language of West and Zimmerman, patients are accountable to gender norms in health care settings. Within the ritual of gynecological exams, providers expect the patient's physical characteristics and gender identity to align with normative expectations of femininity. For some transgender patients, these expectations make what could be a routine procedure into a problematic event. When faced with a transgender patient, medical providers are encouraged by standards of care to implore trans patients to treat the body as it is but are not equipped to cope with the various relationships patients have with their bodies. Further, the medical profession largely accepts “the principle that a natural dimorphism should be established or maintained at all costs … [and assumes] that every body has an inborn ‘truth’ of sex that medical professionals can discern and bring to light on their own” (Butler 2004, 6). These assumptions and the belief that the role of a medical professional is to rectify the problem of trans men in gynecology through an exercise in subtraction (i.e. hysterectomy) fundamentally discounts the diverse embodiments of trans individuals.

This is not to say that health care providers are bad people or are necessarily anti-trans. They are caught in an ideological conflict where medical narratives of risk and the expectation that individuals will make decisions based on the precepts of biocitizenship fall apart when gender accountability is challenged. The solution that might make the most sense to providers (removal of offending organs through hysterectomy to bring biology in line with perceived identity) doesn't work for all trans men. Some want to bear children. Others have no conflict between their identity and their bodies.

The experiences of trans men described here raise the problem of choice in cancer care. When considering preventive cancer care or treatment after a diagnosis, individuals often have a considerable degree of choice in the medical interactions they have. In the remaining chapters, the tension between a patient’s choices and a patient’s health circumstances will be shown to complicate the influence of gender ideologies on medical care and the ways in which medical care legitimates or de-legitimates embodied identity. It is through this tension that the role of medical care in reinforcing the gender system becomes evident as does the possibility of resistance.

Chapter 2

Diagnosis and Treatment

Male breast cancer makes up a small portion of the breast cancer experience, with only 1% of cases diagnosed in men (Speirs et al. 2010). However, incidence of male breast cancer has been increasing in the United States since 1978 (Speirs and Shaaban 2009). In 2011, 2,078 men were diagnosed (compared to 220,097 women). In that same year, 443 men and 40,931 women died from the disease (Centers for Disease Control 2014). In 2014 the CDC estimated that approximately 2,360 men would be diagnosed with breast cancer in 2014 and 430 men would die from the disease (American Cancer Society 2014). Additionally, in a comprehensive study of male breast cancer, surgeon Jon M. Greif and colleagues (2012) found that men have a significantly lower survival rate than women even when diagnosed at early stages of the disease, and that men typically present with more advanced cases (i.e. larger tumors, lymph node involvement, and/or metastases). With increasing incidence rates and a small media presence, male breast cancer is a health concern about which some men are slowly becoming more aware. Five states (Connecticut, Florida, Massachusetts, New Jersey, and Pennsylvania) have declared the third week of October to be "Male Breast Cancer Week," and some major breast cancer activist groups have also made an effort to include men.[1] However, the dominant message of breast cancer awareness campaigns still frames the disease as a matter of women's health, thus rendering men with breast cancer less visible.

Like the trans men in the previous chapter, cis men with breast cancer ostensibly enter a realm of medical treatment and a culture of disease-fighting activism defined by normative

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[1] Susan G. Komen for the Cure partnered with Marvel Comics for the creation of eight themed covers for breast cancer awareness. This partnership also included a one-page advertisement for male breast cancer (Marvel Comics 2008). The Doctor Susan Love Foundation, another breast cancer awareness non-profit, includes the profiles of a few men with breast cancer along the more extensive list of profiles of women.

femininity. In both gynecological and breast cancer care the masculinity of male-identified patients is threatened by both the physical setting of the clinic and their interactions with medical staff. In this chapter I show that while both trans men and cis men are marked as "wrong bodies" within female cancer care, the way that these bodies and identities are managed during medical interactions are experienced very differently by patients. Cultural norms of masculinity become guides for both cis male patients and their providers in navigating breast cancer treatment. Although cis men may have the wrong gender for breast cancer, their gender identities and bodies match. Given this alignment, men trouble treatment norms for breast cancer. In this chapter I explore the ways that masculinity impacts breast cancer treatment for men in ways that serve to reinforce alignment between patient identity, body, and gender norms despite a diagnosis of “female” disease.

Delayed Diagnosis

A breast cancer diagnosis is often especially shocking for cisgender men diagnosed with the disease. Frank expressed the sentiment of many men I interviewed when he described the moment of his diagnosis:

> I'm a man who was just told you have [breast] cancer. And I am floored…. It was just like someone hit me with a two-by-four. … I'm sitting there going, holy shit. I'm a man (laughs) and I have breast cancer.

Acquiring a diagnosis can be a lengthy process for men. Most of the men in this study delayed seeking medical attention after noticing abnormalities in their chests. Several men also explained that when they brought their concerns to primary care doctors, these physicians sought out other explanations. Diagnosing breast cancer in men can be complicated due to the general reticence among men to seek medical care except in emergencies and the relative lack of awareness about male breast cancer among both patients and physicians.

Avoiding Medical Care

Masculine norms about health seeking can have dire consequences for breast cancer diagnoses. Compared to women, men with breast cancer are often diagnosed at later stages of the disease. One explanation for these relatively late diagnoses is the fact that men tend not to engage in routine preventive care (see Pinkhasov et al. 2010 and Vaidya et al. 2012). Courtenay (2000) argues that delaying or avoiding medical care is one way in which men "do" masculinity. Although they didn't directly attribute delaying care to masculinity, most men were candid about the fact that they did not participate in routine medical exams. Ezra stated that he rarely went to the doctor because "I have no complaints… If I don't have a physical complaint, I just don't go to the doctor." Similarly, Henry stated that he only visited a doctor "to treat a broken collarbone or other [sports] related injury." Henry also emphasized his overall sense of robust health. I was always super healthy. I didn't realize that I was particularly vulnerable to anything. And I was always busy." Being busy with children, his spouse, a full time job, and graduate school rendered regular checkups a low priority. James was one of the few proponents of regular medical care and expressed disdain for male relatives who "talk with a kind of bravado, oh I never go to the doctor." "Bravado" here serves as a code for masculinity. When imitating this relative, James' voice dropped an octave and he spoke with a sort of swagger in his voice. Still, James reiterated the sentiment that medical visits were important primarily if something was wrong. "I mean something ain't right, get it checked out. That's my philosophy." Despite these assertions many men in this study delayed care even after they recognized that something was wrong.

Prior to diagnosis, most men noticed some kind of physical abnormality on their chests. Henry felt an unusual pain when putting on a messenger bag. Tim experienced "yelloworangeish discharge out of [his] nipple for a year to a year and a half." Frank, a long distance runner, noticed irregularities in the normal chafing he experienced on runs.

> I was a runner and every now and again a man, when he runs, tends to bleed from his nipples and that's what happened to me particularly on my half-marathon runs. And I noticed that my right nipple started looking funky… like it may have a blister on it or it was changing shape or something.

Despite feeling concern about these abnormalities, men often delayed seeking medical attention. Ezra, for example, discovered a lump behind his nipple and "watched it for a while and went through the denial phase." When Ezra finally decided to get the lump checked out by a physician, he first had to find a primary care physician, as he did not have one at the time. Ezra admitted that he "could have clearly gone to the doctor several months earlier, maybe two or three or four if I would've gone the first time I felt it."

Other men reported ignoring breast abnormalities for anywhere from a few days to a few months. Ted noticed his lump in October of 2011 and "kind of ignored it like most guys would do, for a while. But eventually after maybe six weeks or so, things started to quiet down at work and I decided I'd go to the doctor." Ted went on to explain that he didn't want to "appear to be a hypochondriac … [or] to look foolish" and he also didn't want to "waste the doctor's time." Men in this study rarely believed that the initial discovery of a physical abnormality was worthy of attention. Tim explicitly attributed this delay to masculinity.

> I think it's just us being men. We think that you know, oh, nothing is going to bring me down. You know, I'm healthy as an ox and unless we feel like we're on our deathbed, we don't go to the doctors.

The sentiments expressed above reflect an overarching understanding of the effects of masculinity on men's health (see Courtenay 2000; Doucleff 2013; Oliffe 2009; Rosenfeld and Faircloth 2006; Stibbe 2004; Watson 2000). Peter Criss, former drummer for the band KISS and one of the most visible male breast cancer activists, implores men to forget the "macho crap" and pay attention to their bodies (Park 2009) and not to "sit around playing Mr. Tough Guy. Don't say 'It's going to go away' … It's just important, just go get checked out. It's not like you're going to lose your manhood" (*Rolling Stone* 2009). Criss here is responding not only to the impact of masculinity on care seeking but also to the feminization of both breast cancer and care seeking more generally. In following the advice of Peter Criss, men who are concerned about breast cancer are able to display their masculinity even if they aren't being "Mr. Tough Guy." In seeking care, they must "man up" in order face their fears and discomfort and to confront their health.

The association with delaying medical attention and masculinity is critical here. Although women do sometimes delay treatment when they observe symptoms of breast cancer, the vast majority seek care quickly and studies by medical researchers suggest the delay between initial observation of symptoms and care has decreased due to increased breast cancer awareness (see Bish et al. 2004). Among women, there is considerable variation in patient delay (the time between an individual noticing signs of breast cancer and seeking treatment) with three months or more being the minority experience, and conclude that delays under one month do not adversely affect treatment outcomes, while longer delays do (Arndt et al. 2002; Bish et al. 2004). While both men and women can delay care seeking for substantial lengths of time, the men in this study consistently attributed this delay to their sense of masculinity, even if the delay was only a few days. Although some research indicates assertion increased awareness decreases patient delay, the men in this study show that even with an awareness of male breast cancer they felt that they delayed care and understood this delay in the context of what it means to be a man (Bish et al. 2004).

When men do eventually seek medical care, it is often after the urging of female family members and friends. In his review of empirical literature on the links between care seeking behaviors and masculinity, John Oliffe highlighted what he termed, “reactive self-care;” the practice of attempting self-treatment or asking a partner for advice prior to seeking medical attention (2009, 347). Like many men, Frank described his wife as being "very concerned" about the changes in his body. Often the women in these men’s lives were instrumental in setting up initial medical appointments. After Henry discovered a lump he "kind of freaked out, but not seriously." When he showed his wife "she said, you gotta get it checked." For these men, health care occurs at the urging of their wives who take on the stereotypically feminine role of medical gatekeepers (see Read and Gorman 2010 for a detailed discussion of gender differences in health outcomes, roles, and behaviors).

Ed found his lump after a female friend urged him, via email, to do self-exams. She found her breast cancer after another friend encouraged her to do self-breast exams. Ed's friend subsequently sent an email to all her friends explaining her diagnosis and encouraging others to do self-exams.

> Normally the response to that is one would expect women to be responsive to that but I [decided to] check myself now. [I found] a very small lump, about the size of a grain of sand, or I'd described as a pine nut frequently. I told my wife and she encouraged me to have it examined, and I did so.

Women here serve as medical gatekeepers. It is through their encouragement that men decide to eventually seek medical attention and act in accordance with gender ideologies that set women up as the link between families and medical institutions. Health practices are divided along gendered lines in ways that set up a normative standard in which women support healthfulness by facilitating medical care while men hold a culturally encouraged and potentially false belief in their own robustness and invulnerability.

For many participants in this research, regardless of gender identity, the most important factor in catalyzing an individual to seek medical attention was a family cancer history. For cisgender men, however, this family history was not enough motivation to seek immediate medical attention (and thus to challenge gendered expectations) after noticing an abnormality. Owen noticed a lump while in the shower and was concerned because his mother died of breast cancer at age 37. He still chose to wait until his already scheduled annual physical to ask his doctor about the lump.

> I was going to see my primary care doctor in a couple of weeks anyways so I – when I saw him, we did our appointment and I was just getting ready to leave and I said, "Well I got this lump in my chest." And he said, "oh, take your shirt off, let me see," and you know, he checked and he said, "Yeah there is something there." He told me later that he looked down at my chart and when he saw the family history that my mother died of breast cancer at 37, a little light went on and he said I want you to see a surgeon.

It was unclear from our interview whether Owen would have put off medical care had he not already had an appointment scheduled. Although his delay of a couple of weeks may not have been medically significant, Owen described his actions as delaying care. Henry's reticence to seek care is even more surprising because he not only had a family history of breast cancer, but he had an uncle who died from the disease.

> I went home and I looked down and there was a lump on my chest. I kind of freaked out but not seriously. … I kind of blew it off for about 2 or 3 days… I mean look at me. I blew it off. I didn't even bother noticing it till I was stage 2B and I'm a prime candidate. I mean I was aware, keenly aware, of the fact that men get breast cancer because of my uncle and yet I didn't run to the doctor in a panic. I blew it off for a few days.[2]

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[2] Cancer staging is a practice used by physicians to indicate the size and extent of primary tumors, whether cancer has spread to lymph nodes, and whether or not there are metastases (secondary tumors). Staging helps to determine the course of treatment as well as a patient's prognosis. Cancers can range from stage 0 (carcinoma in situ) to Stage 5 (cancer has spread to distant tissues/ organs). The higher the staging number, the more extensive the disease. Higher numbers can indicate larger tumor sizes and greater spread of the disease to other tissues beyond the primary site. In Henry's case, stage 2B is treatable, however an earlier diagnosis may have yielded a less severe staging, thus improving the prognosis and requiring less extensive medical treatments.

Waiting a few days to seek medical attention is not necessarily unusual. What is notable here is that the reason behind the delay was Henry's assumption that any breast abnormality in men is probably nothing and the fact that men reported the time as a delay. Additionally, men tend to seek care after their wives or other woman in their life encourages them to take medical action. Ideologies of masculinity may influence men's timeline for decision-making even when they have knowledge about male breast cancer due to family history. These norms set a standard for men to be independent, in control of their bodies, and to reject help (Connell 1995; Courtenay 2000; Oliffe 2006). Breast cancer threatens each of these masculine characteristics as cancer indicates a body out of control and requiring medical help. Once men *do* seek help, however, they may be met by medical professionals who delay diagnosis.

Diagnostic Delays

Medical students are often taught the following adage as they begin clinical training: "When you hear hoof-beats, look for horses, not zebras." Aspiring physicians are taught to focus on the most likely diagnosis for a group of symptoms rather than the more unique possibilities. For men with breast cancer, this can lead to delays in diagnosis. Henry was worried about this tendency because he'd "heard [about doctors who] blow off" other men with breast cancer. Henry went on to say that the aggressive nature of male breast cancer is attributable to physicians discounting the breast cancer during the differential diagnosis.[3]

> There is a danger in the medical community particularly in smaller communities or with older doctors where they go, "Oh it's probably just a cyst" and I've met people in talking about that, men who were all the way at stage 4 before they're actually diagnosed even though they had gone to medical professionals in advance. That's just tragic.

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[3] A differential diagnosis is the process physicians use to differentiate between diagnoses that have similar symptoms.

Tim's story is one such example of doctors downplaying the possibility that a male patient may have breast cancer. Tim was also diagnosed at a very young age compared to the average male breast cancer patient; he noticed his lump as a teenager while stretching. When Tim mentioned the lump during a varsity sports physical, the team physician dismissed his concerns:

> [He told me] it's probably just calcium build up. You're going through puberty. Your body is changing. It should go away over the next few weeks or months. It never did.

Tim brought it up again a year later and was told to come back if it changed in size. After college, when Tim secured a full time job with health benefits, he again sought medical attention. Tim's new doctor was suspicious because the lump had been present for over five years. It is critical to recognize that if Tim were a high school aged woman and approached a physician with a lump, it is likely her concerns would be treated seriously and breast cancer would be considered by the physicians even though breast cancer is rarely diagnosed in women this young.[4] For a high school aged woman, breast cancer is never a "zebra" during differential diagnosis because she will always have the "right" body (and gender) for breast cancer. Men, and especially young men, statistically have the wrong body for the disease. Tim could have been diagnosed with breast cancer or condition like fibroadenoma that can become cancerous. [5] In either case, there is a good possibility that he would have been treated early and possibly prevented the growth of a malignant tumor had he been female.

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[4] According to the Susan G. Komen Foundation, fewer than 5% of breast cancer diagnoses occur in women under the age of 40 (Komen 2016b).

[5] Fibroadenomas are solid tumors in the breast and are the most commonly found tumor in young women. These lumps tend to be surgically removed, but if left in the breast can become cancerous. These tumors are part of a larger group of conditions, called proliferative lesions without atypia, that can increase a person's risk of breast cancer. Proliferative lesions with atypia and lobular carcinoma in situ are two additional groups of benign conditions that can lead to increased breast cancer risk.

Although his diagnosis didn't take five years to attain, Frank also faced difficulties convincing his doctor to seriously consider breast cancer as a possibility for him. When Frank asked his primary care doctor to examine his chest, the doctor said "it's probably nothing, I'll send you to a surgeon if you want." Subsequently, the surgeon told Frank the same thing: "it's probably nothing." The surgeon's conviction that there was nothing to be concerned about prevented him from performing any diagnostic tests. A month later Frank returned and the surgeon finally acquiesced to a biopsy that led to a cancer diagnosis.

Even when physicians take the breast cancer concerns of men seriously, often the potential severity of the diagnosis is minimized. Owen's primary care physician also believed that the lump was not a major cause for concern despite Owen's family history of breast cancer. This physician did send Owen to a surgeon but minimized the likely outcome: “He said at worst they'll do a lumpectomy and take it out and send it to the lab and you'll be done with it and I said, ‘Oh, okay.’” The response of physicians is somewhat similar to the masculine bravado James recounted earlier. Sometimes both men and their physicians believe that physical abnormalities in the chest are unworthy of attention. Both may believe that men are largely invulnerable to breast cancer and that there must be a better explanation for abnormalities than cancer.

The downplaying of breast cancer by some men and some of their physicians is, in my assessment, a result of the statistical and narrative framing of breast cancer as a woman's disease. In this initial discounting of the possibility of breast cancer, physicians and patients reaffirm the power of ideas about masculinity to shape men's approach to health care and the actual care they receive with potentially dire consequences for the diagnosis and treatment of breast cancer. As such, they reify cultural norms that pathologize masculinity as risky for men's health and mark men's bodies as wrong for breast cancer. Once men have raised the suspicions of their primary care physicians, they enter a cycle of care defined by femininity. Men and their providers turn to aspects of masculinity that frame them as protectors of femininity. This then grants them right of access to female space of clinic and explains their behaviors once in that space (see Hollander 2001; Westbrook 2008; and Westbrook and Schilt 2014 on the vulnerability of women and their supposed need for protection from the threat of masculinity). Health care professionals similarly turn to ideologies of masculinity to guide their care of male breast cancer patients.

Dissonance in the Clinic

Mammograms are an essential component of breast cancer diagnoses as the resultant images are crucial in assessing the extent of cancer.[6] Mammograms can occur in dedicated breast clinics or in more generalized radiology centers. The general set up of many clinics where mammograms are performed systematically mark men as outsiders. Intake forms use images of women's bodies and language (such as asking whether or not the patient may be pregnant) that reminds men that women are the default patient population for these clinics. After navigating the waiting room, men patients are carefully separated from women patients in the interior space of the clinic, sometimes enduring long waits until the examination spaces are cleared of women. The men in this study interpret this as a rightful focus on women and as an assumption that men would be disruptive to the women patients. At the same time, men reported that individual providers made an effort to help men feel comfortable and to bolster the masculinity of male patients through language and gown selection, for example. The clinical diagnostic experience has two key parts: intake and the waiting room, and the mammogram itself. Although men initially experience the clinic as gender outsiders, providers show a great deal of sympathy

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[6] Biopsies are typically used in conjunction with mammograms to help stage breast cancer.

towards these patients and work to bolster men's masculine identities throughout the diagnostic process.

The Waiting Room

Men are not always prepared to walk into a space intended for women, even after a breast cancer diagnosis. Tim, for example, was taken by surprise when he was sent to a women's clinic for a mammogram.

> So the [doctor] scheduled me for [a mammogram] and I went. I knew exactly the place he sent me. I walk in and they said, "It's the building behind you, not this. This is the MRI place." So I walk in [the other building] and the suite they're sending me to, it's a women's clinic. … I walk into the women's clinic and they needed a clipboard [filled out with personal information]. The first two [questions] it was like, okay, have you been feeling well or sick or whatever. Then they started like when was your last menstrual cycle? Are you pregnant?

These are standard questions before a mammogram, but can be alienating to some men. As for the trans men in the previous chapter, intake forms can be critical in setting the context for patient comfort and trust in their providers. Unlike trans men, however, cisgender men are afforded social recognition throughout medical interactions. That is, although there may be initial discomfort, cis men are seen as and treated by health care providers as men who need care rather than as a curiosity. Although men are not the expected breast cancer patient, they are conceivable to providers because their bodies and identities match. Their bodies don’t need to change, rather the medical interaction needs to change in order to ensure that the medical treatment does not threaten the alignment between patient identity, body, and cultural expectations for gendered bodies. These two groups of men indicate gradations in the wrong body. Both have the wrong gender for the medical care they seek. In the case of cisgender men, the identities and bodies of the patients are aligned with what is normatively expected in a medical exam. They simply were unlucky to be diagnosed with a disease associated with women. In other words, the identities and bodies of cis men are aligned, the bodies (because of the presence of a tumor) align with medical care, but their identities and care do not align because breast cancer care is predicated upon a standard of female identified women. Within the context of the medical exam, trans men are in a position where although their bodies are aligned with gynecological care, their identities are not. Cis men essentially get the wrong cancer, while trans men have the wrong gender. Breast cancer care providers can get over the strangeness of a male breast cancer patient because these men are in a situation that is out of their control. Trans men in contrast, have chosen to alter their bodies in ways that some medical professionals deem strange or confusing. Even if they are comprehensible to providers, men in mammography clinics remain, however, a problem to be solved by health care providers.

The discomfort experienced by men extended beyond just the forms. Larry, who received care at a well-respected cancer research facility with a large male patient population expressed his frustration with women's clinics.

> It's a big issue. The breast center has a very nice big waiting room and I can't tell you how many times I would be called Mrs. "Smith." One time I was there for an ultrasound to check the progress of the chemo and I kept waiting and I kept waiting and I kept waiting and it was like 45 minutes past my appointment and I went up to the desk and I said, I'd just like to know when I'm going to be called back and she said, oh, well let me check –there's a delay because there are a lot of women back there and they didn't want them to get all flustered. … After a mammogram, there's the main doors that you go in and there's like a side door over at the far side and several times they would direct me to go out that – like the back door, so to speak. Because you know the women are sitting in there in gowns in sort of the little waiting room to be called in. I mean you feel strange enough having what's perceived as a woman's disease.

Larry was referred to by the wrong gendered honorific and his presence had to be managed by medical staff in order not to "fluster" the women patients who claimed the space of the clinic. Office staff frequently assumed that Larry was even in the wrong place. When he would step up to the window to register for a mammogram, "the person sitting behind there would say, ‘oh, you need to go to the third window [for prostate screenings].'" For a cis man, these gaffs are annoying and unpleasant but fairly easy to move past. Trans men experience these mistakes as microaggressions stemming from fear or disgust about transgender bodies (Cochran et al. 2007; Lurie 2005; Nordmarken and Kelly 2014). Central to microaggression is the sense that one's identity is invalidated or dismissed. Although they leave an impression, cis men can accept these incidents of using the wrong name or pronoun as unthreatening in part because providers tend to immediately correct themselves and apologize, rather than repeatedly making these mistakes. The gender identity of cis men and their physical bodies are not challenged by medical staff in the same way that those of trans men are. When identity gaffes occur for cis men, medical staff quickly correct themselves. Although their bodies may be wrong for breast cancer and thus require some accommodations by providers, cis men are easily accepted by these providers because their bodies and their identities largely match.

A common response to microaggressions is to alter clinic policies and procedures to prevent these moments of invalidation. For example, intake forms might have an open space where patients can insert their preferred pronouns or gender identity, rather than having only a choice of male or female. Where most trans men advocated for these kinds of changes to the intake forms due to their alienating impact, Ezra diminished the importance of the forms and was almost apologetic about his discomfort.

> It's not a big deal. Most of the patients are women so the forms ask you whether you're pregnant, you know, I mean, you could think of a form that doesn't but you know, I'm not going to insist that they invent one for me.

This dismissal of the forms is, in itself, a way to retain a sense of masculinity through chivalry and a sense of protectiveness towards women. The men I spoke with were very cautious about detracting from women's place at the center of breast cancer discourse. While those in this study were adamant that there was a need for greater awareness of breast cancer in men, they were cautious about causing any affront to women with breast cancer. Given his advocacy for men with breast cancer, Tim felt that this was a concern for breast cancer survivors.

> I'm not trying to take anything away from women. Sometimes, other breast cancer survivors kind of turn their nose. They're like, this is our thing. He's trying to steal our thunder. Absolutely not. I'm not trying to do any of that. I'm just trying to build the awareness that men can get it too. … If we can build the awareness and try to quit having men be so stubborn, and go to the doctor when they feel that something is wrong and not waiting too long, that's what we're just trying to do. … We're trying to, you know, make it pink and blue.

In breast cancer culture, women and femininity are at the center. Larry describes it as "a sorority or a girls' club." This emphasis extends into treatment centers that are designed specifically for women. Although many men and women in who participated in this project were unequivocally critical of Pink Ribbon activism, raising awareness remained an important concern for these participants. Regardless of men's stance on the Pink Ribbon, they, like Tim, recognized the importance of preserving these spaces and breast cancer culture for women.

The Mammogram

Once men navigate the exterior and interior waiting rooms, they then confront the mammogram. The mammogram experience can be difficult because not only are men's bodies "wrong" for the space of the clinic, but the technologies used in breast cancer diagnosis cannot always easily accommodate men's bodies. Mammograms are a type of x-ray used to create images of the breast's interior. While standing, the patient's breast is sandwiched between two plates. Tim vividly remembered the pain associated with mammograms.

> If you're a svelte, small breasted woman or a male it does kind of hurt. … The nurse adjusted the height [of the machine]. She winked and grabbed my nipple … and pulled as hard as she could… and then clamped it down.

Men (and women whose bodies do not fulfill cultural ideals of appropriately breasted women) have difficulty fitting into mammogram machines. Henry laughed when asked about mammograms and said simply, "it's a pretty tight fit." Frank felt fortunate to have "some tissue there so they didn't have a hard time getting me on to the machine." Larry described in greater detail how the lack of tissue was addressed. "They start way around, almost like on your back. They sort of push around from under your arm and gather enough sort of whatever to put it in the machine. It was strange at first. I'm used to it now."

Lack of tissue isn't the only complicating factor when men receive mammograms. The location of body hair led to a humorous first experience for James.

> The first one was rather hysterical. Because (laughs) I have a really hairy chest and I don't have large man boobs (laughs), okay? And when I was there for the mammogram, we get it into the device and crank it down and it would pop out (laughs) because of the hair. And what would normally be like a five-minute ordeal for a woman turned into a 20-minute thing for me.

Mammography machines are designed for easily accessible, hairless breasts. Given that mammograms are often held in women-centered clinics, everything from intake forms, to physically navigating the clinic, to the exam itself can be alienating for men. There are constant reminders that men’s bodies are wrong for the space and care that these clinics provide. Ezra admitted to feeling "a little odd" and "a little weird" at the breast clinic. He believed that this was a common experience for men who "experience cultural dissonance when they go into this very female environment." Mammograms are but one possible imaging technique for diagnosing breast cancer. Alternative imaging techniques include ultrasound and MRI. Recent studies with women suggest that ultrasounds can be more effective screenings for “node-negative” tumors (those that have grown past the initial tumor but have not invaded the lymph nodes) and are often used to distinguish between benign cysts and cancer. While this type of imaging might be more comfortable for men, the high rate of false positives associated with ultrasounds and the potential for this screening to miss cancers readily detected by mammograms has obstructed their widespread use as an initial imaging option (American Cancer Society 2015; Berg et al. 2016). Ultrasounds are considered more difficult to interpret for men, due to their relative lack of breast tissue (Contractor et al. 2008). Instead, ultrasounds are recommended as a supplement to the more standard mammogram. In addition to the false-positive rate, ultrasounds can also miss cancers that are readily detected by mammograms. Magnetic Resonance Imaging (MRI) is a third imaging alternative during which the patient lies on a special table with spaces cut out for the breasts. These tests take much longer than other imaging and require the patient to lie as still as possible, thus presenting additional obstacles to testing. Additionally, breast MRI is not available at all imaging centers, nor are all radiologists trained to read a breast MRI. These exams can also be expensive and are not always covered by insurance (American Cancer Society 2015; Komen 2016a). Because of the limitations of other screening methods, mammograms remain the first line of screening and diagnostic imaging.

Male breast cancer activist Harvey I. Singer argued that the cultural dissonance men experience was evidence that "the medical community was not set up to handle guys with this disease" (HuffPost Live 2012). To a certain extent, the medical community is aware of this issue and individual providers can be instrumental in alleviating the dissonance felt by men with breast cancer[7]. While intake forms and front desk staff often initially caused dissonance for men, participants told me that technicians were careful to reassure men of their masculinity through language choice and the selection of mammogram attire. Ezra's radiology technician assured him

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[7] Until 2010 there were no randomized clinical trials of men with breast cancer. One such study was attempted but the research team was unable to secure clinical sites and research participants interested in the trial (Kordell et al. 2010). As of February 26, 2016 the World Health Organization Clinical Trials Registry lists 97 clinical trials for breast cancer in men in the United States (World Health Organization 2016).

that "they do men all the time." Henry's technician provided reassurance by continually referring to the imaging as a "man-o-gram." When Larry went for his first mammogram he was surprised and comforted by the efforts of the technician to make him feel at ease.

> The technician was thoughtful enough to go dig in a cabinet for a tattered blue basic, little patterned gown like you get at the doctor's office instead of just pulling a pink gown from the stack that was out on the counter.

These efforts are symbolic gestures indicating that the male-bodied patient was accepted in this generally women specific space. This was an experience that Joe, a trans man in the previous chapter, also had. In both cases, the gown color was a gesture by the medical provider indicating that the patient’s gender identity was respected within the medical interaction. Both Larry and Joe also were separated from the typical woman patient. Joe did this by choice in order to avoid feeling uncomfortable in a gynecology clinic. Larry was separated by the providers, thus marking him as a potential threat to women patients. The specific experiences of Joe and Larry reflect the ways in which normative masculinity can be used symbolically by providers to put men at ease in medical exams defined by women patients. The trans men in the previous chapter indicate, however, that this is rarely their experience while several cis men explained how their providers worked to ensure that they did not feel out of place. Because their bodies and identities make sense, even if they are out of place in the context of treatment, cis men are able to benefit from normative masculinity in medical interactions in ways that trans men cannot.

Another way to navigate the dissonance of being a male body in a female centered space is “discursive distancing.” Sociologists C.J. Pascoe and Tristan Bridges explain that “as men are distanced from hegemonic masculinity, they also (often more subtly) align themselves with it” (2014, 250). Bridges and Pascoe argue that discursive distancing is one aspect of contemporary hybrid masculinities that include pieces of marginalized and subordinated masculinities and femininities (2014, 246). It is important to recognize that even when men create distance from hegemonic masculinity, as when the men in this study insist that they aren’t “macho-man types,” these hybrid masculinities are still “reiterating gendered relations of power and inequality” (Bridges and Pascoe 2014, 252).

In being diagnosed with breast cancer, men are incorporated into a feminized medical interaction. In this case, the men I interviewed not only distance themselves from hegemonic masculinity in order to explain why a breast cancer diagnosis wasn’t threatening to them but also distance themselves from the femininity that is associated with both a breast cancer diagnosis and its treatment. One discursive tool used by the men I interviewed was a refusal to refer to the body part in which cancer was found as "breasts." Instead, men used the word "chest", save for one participant who referred to his "man boobs." As Mark stated, "I didn't even have breasts. I just had a chest." Nearly as commonly, men avoided using specific language to refer to that part of their body. By refusing to name this part of their bodies (or by adding the prefix "man"), men are relying on normative expectations of male bodies to make sense of their breast cancer diagnosis while also distinguishing themselves from women with breast cancer and body parts marked as feminine. These expectations are brought to the fore and are reinforced when interactions between men and medical professionals are mediated by technologies and treatment procedures that are embedded within expectations about femininity and female bodies. In other words, the men I interviewed described a general assumption that the diagnostic procedures for breast cancer would be awkward. The only reason for this awkwardness is because breast cancer diagnostic care is predicated on an ideal of a female-bodied, feminine identified patient. When the patient is male-bodied and masculine identified, the diagnostic protocol begins to unravel. As a result, some providers turn to and some patients are comforted by behaviors that acknowledge a male patient’s masculinity such as a blue gown or altering language from “breast” to “chest, or “mammogram” to “man-o-gram.”

Encroaching Femininity

Men with breast cancer typically have a mastectomy, although in occasionally lumpectomy or “breast conservation” may be an option. Lumpectomies are rare given the relative lack of breast tissue in men. For men, the main difference between a lumpectomy and a mastectomy is the removal of the nipple during mastectomy (for more on surgical treatment option for men see Golshan et al. 2007 and Kordell et al. 2010). Where women sometimes have to make the decision about which surgical procedure to perform, most men simply submit to a mastectomy. As Frank's surgeon told him, "You're a guy. It's a rather simple decision." The idea that mastectomy is an easy decision for men implies that breasts are meaningless to many men in terms of personal identity or their sexuality.

Several men reinforced the idea that mastectomy was easier for them than for women. Mastectomy was generally reported as being "a piece of cake." Ezra, like many others, assessed his response to surgery in comparison to what he imagined to be the response of women.

> I think for a woman psychologically it's just very, very hard. Going through a single or double mastectomy affects them a lot more psychologically because it is so wrapped up with your image as a feminine person and you know, that's a sex organ they are taking away. It makes a big difference. For guys it's just an inconvenience and you get going again, I mean it's not that bad.

Ezra's comment suggests that connecting one's identity to the missing breast is the realm of women and not men because of the importance of this one body part to various aspects of female identity, most notably sexuality. As in other aspects of treatment, this perception reinforces hegemonic masculinity in that men’s sexuality is not located physically in their breasts (despite these being erogenous zones). Such a separation serves to distinguish men from women, a key aspect of hegemonic masculinity. In their study of cosmetic surgery, Dull and West argue that accounts of cosmetic surgery turn on “implicit claims that what was ‘normal’ and ‘natural’ for a woman was *not* normal or natural for a man” (Dull and West 1991, 64 emphasis in original). They additionally note that “surgeons were united in the view that women’s concerns for their appearance are *essential* to their nature as women” (ibid.). Men’s lack of choice in reconstructive surgery reflects the overall sense that breasts are not essential to men, that reconstruction is the particular domain of women, and therefore cosmetic surgery cannot help restore any manhood lost due to the experience of breast cancer. Obstructing men’s access to reconstructive surgery after mastectomy reifies heteronormativity by reinforcing the distinction between men and women as located in the body and more specifically in erogenous zones of the body.

While most men in the study discussed their mastectomy in matter of fact terms, several described the emotional difficulty connected to their surgically altered bodies referring to their bodies as "alien." Experiencing the body as alien complicates the notion that mastectomy is a simple decision for men. Ed tried to explain what it felt like to lose sensation in a part of his body.

> The appearance felt alien for a bit. I'm looking at something that's not part of my body, and initially I didn't want to touch it because of the sensation there you know when I did touch it, it wasn't me because I couldn't feel anything. But clearly it was me, so there was a little divorce from that – a little separation from that side of my body for about a month. It just happens to be there on me but isn't really me. But now it's me, you know, I'm pretty comfortable with it being there. … I'm feeling around to make sure I can feel other parts and then as I touch into that area, I know I'm touching it, but I don't feel it on my chest. I can feel my finger touching something, but I don't feel the responsiveness. I don't feel my chest. … The first word that came to mind is dead part of the body or unresponsive part of the body. … It's a part of me, but a part where there's no sensation.

The lack of sensation is a common issue for male and female breast cancer patients. Even though many men don’t identify with their nipples, losing physical sensation in any part of the body can be an unsettling experience.

Along with a lack of feeling, mastectomies often result in significant scar tissue at the surgical site. While this is the case for both men and women after mastectomy, there are significant differences in the embodied experiences of healing. Often men were able to ignore their scars because chest hair covered them. Regardless of chest hair, men typically are not offered any reconstruction options whereas women are strongly encouraged to undergo this additional surgery.

Larry believed that the nonchalance concerning mastectomy was the product of how men are supposed to feel about their bodies, rather than reflective of the actual experience of breast cancer. He also connected reconstruction with cultural associations between women and breasts that render invisible any connection a man may feel to this part of his body.

> The comment was made to me by a variety of people that well, I guess it's not such a big deal to have breast cancer for men because you know, they don't identify as women do with their breasts and all that and it's true, you don't – first of all you don't deal with the reconstructive issues, decision and issues. Because generally in men, you know, you don't do reconstruction. I still get out of the shower every morning and you know, my body is altered. So there is still a psychological aspect of you know, having the mastectomy.

Ed described his chest as concave after mastectomy, yet no physician offered an implant to fill the space. Most men in the study had difficulty imagining why a man might want reconstruction. Ed mentioned reconstruction to his surgeon as a joke. He followed this story by stating, "if it were important to my career, if I were a trainer as I see in the gym, I want [reconstruction], I want to look good for prospective clients, current clients." Only Tim discussed considering any kind of reconstruction.

> When I was first diagnosed and everything, I did meet with a plastic surgeon … to talk to him about it, and he was like, well I've never really done anything for a male, but you know, I can tell you the options of this, this and that and everything, you know, the reconstruction of it. They take skin and they try to like grow a new nipple, or you'll get it tattooed back on or whatever. After I met with him and stuff, you know, I kind of let that sink in. I was like, that's just a lot of weird, whatever, you know what? After surgery and stuff, this is going to be my battle wound. This is a battle that I fought. I won. I really don't want to forget about it, so that's what it is.

Tim was the youngest man interviewed and also had a job where his chest would be visible to others. His concerns about his career were similar to Ed's belief that some men might be professionally impacted by a disfigured chest. The shift from viewing his body as disfigured to viewing it as imbued with battle scars signifies a masculinized perspective on breast cancer. Even though the men in this study eschewed a macho identity, the language of battle scars allowed some of them to interpret their scars not as markers of breast cancer but as markers of survival. A narrative of survivorship and battle scars is present in breast cancer culture at large (Mukherjee 2010; Sulik 2011), and for men it is a distinctly masculine way to connect with that culture.

Accepting and reinterpreting scars was important for male breast cancer survivors because reconstruction generally isn't an option for men. Frank's surgeon told him:

> You're a man. We'll remove the breast and that will just be the end of it. For a woman, he said there'll be other issues but they are usually not an issue for a man. That would be the end of the discussion.

Larry's surgeon told him that reconstruction "is available but generally men don't do it." His surgeon told him of one patient who was a swimmer and chose to get a nipple tattoo. This was the most common option for men, but no men in this study had one. Most found the idea of a tattoo humorous. In describing his scar, Ezra said:

> It's a very nice scar. It's as unobtrusive as a scar like that can be. … I'm still contemplating getting some kind of nipple tattoo, but I'm not sure yet. I'm kidding (laughs). Only if I can put something rude there (laughs).

Ezra went on to say that a tattoo was just "too much" and wondered, "Who would see it anyway?" Men in this study found little value in tattooing. Other forms of reconstruction were vaguely understood by men and offered little in terms of their personal comfort with their chests.

Men also expressed concerns about how others would react upon seeing a scarred chest. Across interviews, it was clear that appearance matters to men, but the imperatives of masculinity create a social context that encourages them to reconcile their concerns fairly quickly. Ed was concerned about how his clothes would fit after surgery and was relieved that his small stature helped mask the concavity present after mastectomy.

> I'm a small guy… In the past I always thought that was a disadvantage. Turns out to be an advantage. I can wear any kind of shirt I want whereas a bunch of the men I see at the gym I go to, if they wore my clothes they'd look awfully funny if they had a mastectomy.

Ed was worried about how he looked because he did not want to "cause people any queasiness." Frank also expressed his concerns that "people would look at me funny" and so wore a shirt while swimming for two years after surgery to prevent causing strangers unease. Rather than focus on others, Frank described his feelings of shame about his post-surgery body. "I'm deformed…. I'm a man that's missing a breast. I'm a man that had breast cancer. … And I'm deformed." Over time, his feelings of shame gave way to a sense of acceptance. Where once Frank feared people staring at him, he eventually took pride in his appearance: “I want them to look at me and I want them to come up and say, What the heck is that? So I can make them aware that there is such a thing [as male breast cancer].”

Other men denied that physical appearance mattered much to them. For Larry it "was not a body image thing." Ezra similarly stated, "I'm way past the age where physical appearance is a big deal." For both Larry and Ezra de-emphasizing body image was connected to their advancing age. Larry talked about how young "pumped up" men might be more focused on the appearance of their chests whereas older men are less concerned about that component of their appearance. Yet each of these men described various feelings of discomfort after surgery. Owen compared the body image issues of women and men with breast cancer.

> I don't think it's as big an issue as it might be. I don't think our issues are that much different from the women except for the whole issue of reconstruction which we don't really have to worry about. There is a certain amount of body image, you know when they cut you up, you're cut up. And for men it – or at least for me it took a year or two before I could go on a beach without a t-shirt and be comfortable enough to wander around.

As for many men in this study, swimming was a major context that raised concerns about their bodily appearance. Owen had a particularly disfiguring surgery. His primary care physician, upon examining the incision exclaimed, "Jesus! They cut you in half, didn't they?" It is difficult to imagine a male physician saying this to a female patient. Normative ideals of masculinity create a sense of presumed distance between a man's identity and his body. While mastectomy scars are initially jarring, men like Owen felt that the mastectomy scar "is what it is" and doesn't require a great deal of attention. Men report intimate partners, both male and female, being uniformly supportive in that partners assure men that they "look great" after surgery.

Mastectomy is a defining experience of breast cancer for most men and many women. This surgery is framed by breast cancer activist culture as particularly detrimental to normative femininity. Men therefore do not have a ready narrative via breast cancer culture to help make sense of their experience of mastectomy. Instead they can rely on masculine tropes that encourage them not to get caught up in their body image. This is not to say that masculinity is protective against body image issues. Instead, hegemonic masculinity places pressure on men to "both achieve culturally privileged bodies at the same time that they are interpellated to maintain a functional, aloof, and distanced relation to their bodies" (Norman 2011, 432). The body is thus a resource by which to access or lay claim to the privileges of hegemonic masculinity. However, the emergence of “aesthetic masculinity” prioritizes bodies that appear young, strong, and vibrant (Atkinson 2008). Given that average age of men with breast cancer is 68, some of the pressures of aesthetic masculinity are lessened (American Cancer Society 2014). Additionally, the scope of what counts as an acceptable male body is fairly broad with everything from scars and “Dad Bods” (i.e. a slightly out of shape figure) portrayed in the popular media as acceptable. For the men in this study, as long as they didn’t make anyone uncomfortable, then their post-mastectomy bodies could become unremarkable over time.

Masculinity Threatened

Most men indicated that they did not feel that their masculinity was threatened by their breast cancer diagnosis. Often, in response to this question, men would distance themselves from cultural norms of masculinity claiming, as Ted did, "I've always been comfortable with who I am and I certainly don't think of myself as particularly macho." Ed distanced himself by virtue of his small stature. What had previously prevented him from claiming certain masculine privilege became, after mastectomy, a mark in Ed's favor because being small camouflaged the damage to his chest.

> I felt fortunate that I never had a big chest. I'm a small guy. I'm five foot five and a half. Some people my size have had well developed torsos and I don't. So something that in the past I always thought was a disadvantage turns out (laughs) to be an advantage.

Not only was Ed physically small but he was also an avid ballroom dancer, an activity not currently considered especially masculine, particularly for a white man (Craig 2014). According to Ed, his unconventional masculinity protected him from feeling threatened as a man by his diagnosis.

Larry was careful to assert that breast cancer did not threaten his masculinity. Like Ed, Larry's identity was outside the scope of hegemonic masculinity. For Larry, the process of grappling with his sexuality and gender as a young man left him extremely secure in his masculinity as an adult. As a result, his breast cancer diagnosis was unsettling but didn't disrupt his sense of masculine identity.

> Being a single gay male as I was at the time and had lived my adult life, you know, it has an added sort of twist to oh, that's a woman's disease. … But in no way has it threatened my manhood. … I don't remember a time in my life when I wasn't dealing with my sexuality. It's not like oh, this makes me less of a man to have breast cancer.

For Larry, coming to terms with his sexuality included grappling with his gender identity. "There were influences within the family that – I saw being feminine or being a woman was more ideal. And so I went through times when it was like, questioning you know, being – being male." Larry describes dealing with these aspects of identity as eventually allowing him to develop a sense of security in his masculinity, though he acknowledged that his way of being a man differed from hegemonic ideals. R.W. Connell uses gay masculinity as the key example of subordinated masculinity and argues that this subordination often includes a "symbolic blurring with femininity" (1995, 79). Over the course of Larry's life, he was able reconcile the socially constructed connection between being gay and being feminine with his own version of masculinity. This process allowed him to understand himself as "a man dealing with a woman's disease" without questioning his masculinity.

Ted recognized that breast cancer might be threatening for some men, but not for him.

> I think there really is an element for men that it's difficult to accept that you might have this disease that's always associated with women and rightfully so. And I think for probably most men that would make them feel at the very least uncomfortable. I can't myself say that it has affected me that way.

Ed, Larry, and Ted each frame their diagnosis around their understanding of themselves as atypical or non-macho men. Although they acknowledge that breast cancer could be problematic for other men, they feel protected from such threats because they situate themselves outside hegemonic norms.

While the men discussed above deny that a breast cancer diagnosis threatens masculinity, the non-surgical treatments for the disease were often framed as threatening. Chemotherapy and hormone therapy (used in the treatment of estrogen positive tumors[8]) sometimes pose a threat to the masculine identities of men in this study due to the associated complications for sexual virility. Several men mentioned, but were reticent to discuss in great detail with me, the effects of Tamoxifen on their libido and their relationships with significant others. [9] Ed stated simply, "It's been fine except for one thing [and] that is a decrease of libido. (pause) [My wife and I] worked through that and we're fine." Ed declined to comment further because he was at work and initially agreed to discuss the matter over an email exchange. He later decided not to comment further. Ted was concerned about this and other side effects of Tamoxifen, but was relieved to have no side effects. In our conversation he mentioned a study he had read that stated that 20% of men stop hormone therapy due to side effects such as weight gain and sexual dysfunction (Pemmaraju et al. 2012). Larry was among the most candid in discussing this side effect. He explained, “The Tamoxifen, it definitely impacts your sexual desires and performance. Some men go off of it because of that. Some men don't ever go on it because there have been no clinical trials.”

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[8] Breast cancer can contain proteins that respond to signals from estrogen or progesterone. These signals encourage tumor growth. Hormone therapies like Tamoxifen (the most common form of hormone therapy) block those signals and prevent tumor growth, others prohibit the production of estrogen.

[9] Tamoxifen is a hormonal treatment for estrogen positive cancers. This drug blocks estrogen activity in some cells, thus helping to prevent estrogen positive cancer cells from growing. Tamoxifen can also act like estrogen in other tissues thus leading to potential sexual side effects for some men.

The combination of sexual side effects and uncertainty about its efficacy in men led many to avoid hormone treatment. Larry went on to say that Tamoxifen has impacted his sexual performance.

> It definitely has an impact. I mean I'm 67 so, you don't know whether (laughs) you know a change is because you're getting older or what. But it is a real issue that I've had to deal with since the cancer diagnosis and the follow up medication.

As breast cancer typically is diagnosed in older men, their sexuality can be doubly impacted. Given the importance of sexual performance to masculinity, hormone therapy for breast cancer is one of the most problematic aspects of breast cancer care for some men. Virility is an increasingly important characteristic of the healthy male biocitizen (Gurevich et al. 2004; Loe 2004, 2006; Wienke 2000, 2005, 2006). The threat to this component of masculinity due to hormonal therapy for breast cancer was one of the most difficult aspects of the disease according to the men I interviewed.

Both Larry and Owen also discussed hot flashes as an unpleasant side effect of Tamoxifen. Owen generally described Tamoxifen treatment to be "a unique experience for men" due to the menopause-like symptoms caused by the drug. The side effects Owen experienced were compounded by his prostate cancer diagnosis four years after starting estrogen therapy for breast cancer.

> The prostate cancer of course leaves you (pause) well you're infertile, you're sterile. Not that I plan on fathering children but psychologically it's just an adjustment. … I think one of the hardest effects of prostate cancer [is] probably an accumulation of 30 years of diabetes, chemo and Tamoxifen, and then prostate surgery, sort of the trifecta of erectile dysfunction.

There wasn't much Owen's urologist felt would help the situation given his overlapping medical issues. According to Owen, "You're not able to have what people would consider a normal sex life. … It is what it is. You do what you can. You still have a lot of closeness. You have a lot of physical touch. … You do what you can." Larry also emphasized alternate forms of intimacy. "With an understanding partner cuddling can go a long way."

Sexual performance is an important component of masculine identity (Loe 2006). The side effects of breast cancer treatment on men’s ability to have penetrative sex with a partner are perhaps the clearest area in which masculinity is threatened by breast cancer. This is evident in the inability of many men to discuss this aspect of their experience. Sexual performance also underlies some of the comments men with breast cancer receive from others. Henry's ability to father children was implicated in a question from an acquaintance: "I had one person who seriously asked me if my kids were my kids because he thought if I got breast cancer I must have been some kind of hermaphrodite."

The implications of breast cancer for a man's sexual identity and the difficulty that some men have in talking about this aspect of their experience are indicative of normative masculine identity. While sexual bravado is a socially accepted masculine behavior, talking about one's inability to perform sexually (except in the context of commercials for drugs like Viagra) is a hetero-masculine taboo. To admit to sexual dysfunction, particularly if not combating it through the use of pharmaceuticals, is to admit to diminished masculinity. While several men claimed that breast cancer did not threaten their masculinity, their statements about the sexual side-effects of treatment suggest otherwise.

Discussion

The diagnosis of a major medical condition tends to redefine an individual in terms of their disease (Kelly and Field 1996; Little et al. 1998). In the case of breast cancer, the experience of the disease, from diagnosis to recovery, is saturated with femininity. Regardless of whether men in this study identified with hegemonic forms of masculinity, they all drew on various masculine tropes in order to cope with their experience of breast cancer. Central to the construction of various masculinities is their differentiation from femininity (see Chodorow 1971, Connell 1987, 1995; Connell and Messerschmidt 2005). The often nonchalant attitude about being a man with breast cancer, careful language choices that distance men from the experience of breast cancer, and a reticence to talk about the impact of masculinity are all techniques for asserting a normative masculine identity, yet the careful effort to distance men with breast cancer from women with the disease, medical interactions reinforce the distinction between "patterns of masculinity" and a "model (whether real or imaginary) of femininity" (Connell and Messerschmidt 2005, 848). Even though the men in this study distinguish their lived experiences from dominant understandings of masculinity, their accounts of breast cancer show how normative expectation about men's bodies, derived from hegemonic masculinity, shape their cancer care. In turn, these medical interactions effectively create "legitimating stories" that act as "justifications for existing systems of power and inequality" (Bridges and Pascoe 2014, 256). These are stories of appropriately gendered bodies that shape and are reinforced by medical care.

Men with breast cancer also represent a disruption to the feminine norms of breast cancer culture. The same techniques that the men in this study and their health care providers use to minimize the threat to the masculinity of these patients also help to manage the disruption of femininity. Men reported that they were uninterested in changing intake forms, had minimal participation in breast cancer support groups, and were shuffled through medical facilities in ways that shielded women from their presence. Effectively they were kept out of these woman centered spaces to both preserve their presumed masculine identity *and* the feminine culture of breast cancer care. The ways in which men discuss their experiences of breast cancer suggest that the presence of this disease in men is a perceived as a threat to the dominant feminine culture of breast cancer care and activism. Their narratives also indicate that masculinity can be deployed to minimize this threat and to help men cope with the experience of having a "woman's disease."

Men with breast cancer, particularly as a result of hormonal therapy, may represent a state of "precarious masculinity" that represents both a loss of masculinity and an escape from the rigidity of what it means to be a man" (Gurevich et al. 2004, 1605). Although this term initially referred to the discourse of men with testicular cancer, I contend that this precariousness also has a place within Connell's constellation of hegemonic, subordinate, and marginalized masculinities and the related concept of hybrid masculinities (Connell 1987, Bridges and Pascoe 2014). In Mimi Schippers' interpretation of Connell's theory, subordinate masculinities are "conflated with femininity" (Schippers 2007, 88). The efforts of medical professionals to separate out the experiences of men with breast cancer from women (in spite of the fact that all clinical evidence is based on women) buffers this encroachment of femininity on the male body. In both clinical interactions and in their intimate relationships outside the clinic, men with breast cancer and their providers reinforce hegemonic masculinity even as men attempt to distinguish themselves from it. Providers in the clinic rely on normative assumptions about masculinity and femininity to bolster the masculinity of patients and to distinguish men from women in the context of breast cancer care. The case of male breast cancer also suggests that clinical interactions reinforce the connection between men's bodies and masculinity, and women's bodies and femininity.

Chapter 3

Choosing Mastectomy

Elective prophylactic mastectomies rates have risen steadily for more than a decade and are in increasing demand as a preventive breast cancer measure (Grimmer et al. 2015; Hawley et al. 2014; Tracy et al. 2013; Tuttle et al. 2007; Zeichner et al. 2014). This surgical technique is characterized by the removal of both healthy breasts (bilateral prophylactic mastectomy) or by the removal of the remaining healthy breast after a breast cancer diagnosis (contralateral prophylactic mastectomies). Part of the rise in prophylactic mastectomies is due to increased availability of genetic testing for BRCA mutations and a growing medical consensus that the surgical removal of the breasts is one appropriate treatment for this anomaly. While bilateral prophylactic mastectomies have become an increasingly accepted form of treatment for BRCA positive women, contralateral prophylactic mastectomies remain highly contested. Ostensibly, bilateral and contralateral prophylactic mastectomies are the same surgical procedure: the removal of healthy breast tissue for the prevention of a future incidence of breast cancer. Yet, the experience of accessing these surgeries differs greatly for BRCA positive women and women with breast cancer. Although biomedical literature argues that the key differences between these two surgeries have to do with risk assessment and health related quality of life, interviews with women who choose prophylactic mastectomies suggest that this surgical treatment is viewed by many health care providers and patients through cultural ideologies about what counts as a normatively female body.

American medical practitioners generally reject the removal of healthy tissue unless there is a significant statistical risk of that tissue becoming diseased over time (as is the case with BRCA). From this perspective, contralateral prophylactic mastectomies are unnecessary because these surgeries do not reduce breast cancer risk (Hawley et al. 2014; Jin 2013; Katz and Morrow 2013; Rosenberg and Partridge 2014). Unless cancer is present in both breasts, physicians will not typically recommend a bilateral mastectomy and some will refuse to perform prophylactic mastectomies. Instead, providers will advocate for the removal of the diseased breast while leaving the healthy breast intact.

Despite these reservations, many breast surgeons will perform prophylactic mastectomies for women diagnosed with breast cancer, not just those with a genetic predisposition for developing cancer. One study of contralateral prophylactic mastectomy argues that surgeons may be prone to "acquiesce to a patient's preference for more aggressive treatment" because they fear "adverse consequences in their practice" like losing the patient to another practice or decreased overall practice volume (Katz and Morrow 2013, 794). Other medical studies suggest that while patients claim that their decisions about prophylactic mastectomies stem from a desire to minimize risk and maximize quality of life, the appropriate course of action for physicians is to provide greater counseling in order to decrease rates of this surgery (Hawley et al. 2014; Jin 2013; Katz and Morrow 2013; Morrow et al. 2014; Rosenberg and Partridge 2014). According to these physicians, providers are obliged to provide better information about the risks of prophylactic mastectomies and to mitigate the fact that "anxiety and fear certainly hamper optimal decision-making" (Rosenberg and Partridge 2014, 589). The medical community remains hesitant at best about prophylactic mastectomies despite the fact that patients report an overwhelmingly positive reaction to the surgery with as many as 90% in one study claiming that they would make the same decision again (Jin 2013, 1548). However, physicians Steven J. Katz and Monica Morrow argue that such claims about patient quality of life after prophylactic mastectomy "cannot be tested because patients cannot be randomized to the surgery" (2013, 794). The argument from the medical community is essentially that bilateral mastectomy does not significantly decrease risk of a second primary breast cancer and patient statements about quality of life cannot be trusted.

Women with breast cancer and biomedical researchers stand in conflict over the appropriateness of bilateral mastectomies. When women choose this surgery, they are largely making decisions on their assessment of how various treatment plans will impact their health and quality of life. The experiences of women who choose prophylactic mastectomy and the assertions of medical researchers that these experiences do not constitute suitable data suggest a fundamental conflict between the medical principles of evidence-based medicine and patient-centered care. Patient-centered care suggests that patient statements should be trusted and have a strong impact on care, yet evidence-based medicine fundamentally discounts the credibility of patient provided evidence about the impact of various treatments on her quality of life

At stake for women with breast cancer and women with BRCA diagnoses in this conflict over bilateral mastectomies are patient claims to bodily autonomy, that is the ability and right of patients to make decisions about the care and future composition of their bodies. The interview data discussed in this chapter explores in greater detail what patients who choose to undergo a prophylactic bilateral mastectomy mean by “quality of life” and the ways in which these meanings factor into decisions about mastectomies. For participants, the most important considerations in choosing mastectomy were fear of future health risks, impact on their ability to parent, and their self-image. Each of these themes contributed to a woman's sense of her quality of life but are largely lacking from the biomedical literature on bilateral mastectomy. Such research focuses only on medical risks (with no consideration for the emotional risks associated with ongoing screening) and fails to account for more subjective indicators like a woman's self-image. In this chapter, I compare the experiences of women with breast cancer and women with genetic predispositions for breast cancer to show that the medical narratives of risk and quality of life that shape access to prophylactic mastectomies are rooted in ideas about appropriately female bodies. Women who choose prophylactic mastectomy often violate these norms and as such confront a medical system that often makes it difficult for them to pursue desired treatment.

The majority of women diagnosed with either BRCA or breast cancer in this study chose to undergo bilateral mastectomy. Four participants underwent the surgery due to the presence of cancer in both breasts (Ellen, Ashley, Suzy, and Judy). Of these four, one woman (Ashley) had primary cancers in both breasts. For the other three women, cancer metastasized (i.e. spread) from one breast to the other. Yet, even with this medical risk, the decision to undergo bilateral mastectomy can be difficult because breasts have many meanings both culturally and individually. Karen neatly summarized what she saw as the most common features of breasts,

> I thought they were fantastic. I thought they were just amazing (laughs). They were like kind of magical [because they could instantly soothe my children]. In my mind, breasts are for breast feeding and they are for sexual pleasure and they are for conforming to some sort of norm about what a woman's supposed to look like. And in those three areas, mine were very successful.

For Karen, breasts are magical, functional, and that which provides the "look" of femininity. Not all women experienced their breasts in this way, but these three functions of breasts represent normative ideals of female bodies. Yet in the wake of a breast cancer diagnosis, breasts also are an object of fear.

The women I interviewed identified four key factors in their decisions to have bilateral mastectomies: perceptions of health risks, parental concerns, the support of spouses or intimate partners, and aesthetics. Each of these is a distinct contributor to the overall quality of life these women experienced following diagnosis. While these factors are rooted in fear, the women I spoke with related their fears to long-term quality of life concerns. Fear and quality of life are well accounted for in literature on breast cancer, yet this qualitative evidence is largely discounted by the medical profession (though individual providers certainly have their own opinions). In this chapter, I compare the accounts of BRCA positive women and women with breast cancer who have chosen mastectomies. Although their rationale for undergoing surgery is similar, the response by medical professionals differs significantly between the groups.

Perceptions of Health Risks

Fear of future cancer in a healthy breast was the most frequently mentioned factor in choosing bilateral mastectomy for the women I interviewed. Fran, a retired scientist who had a history of suspicious mammograms, chose to undergo a contralateral mastectomy after a breast cancer diagnosis. About this decision, she stated, "it was just like I've had enough of this. … I just wanted to get rid of the whole situation. I just don't want this worry all the time." For Fran, the yearly cycle of a suspicious mammogram followed by various additional tests created a great deal of anxiety. A pragmatic scientist, she ultimately decided that removing the breast tissue would remove the worry associated with annual mammograms of the remaining breast. Fran’s fear was echoed by many women in this study. A history of abnormal mammograms combined with sometimes numerous rounds of follow-up tests created intense stress. Choosing a bilateral mastectomy meant an end to this annual cycle of concern.

Colleen had a unilateral mastectomy and decided to have a contralateral mastectomy after a period of living with one breast. For her, the decision to have the other breast removed came after she became "fed up with everything, everything about breast cancer, and everything about screening and everything about all the MRIs and scans and everything."[1] Contrary to the common belief that early detection is the best defense against breast cancer, Fran and Colleen indicate that these measures are invasive, anxiety provoking, and ultimately detract from their overall quality of life. These two women represent an association between increased surveillance and ongoing emotional distress. Further, these screening methods are hotly debated in the news media, as researchers differ on the efficacy of various technologies for identifying cancer early (Elmore et al. 2015; Kerlikowske et al. 2013). Women who chose bilateral mastectomy felt that the scientific uncertainty and emotional turmoil of the tests were more discomfiting than removing their breasts.

Other women expressed doubt that other breast cancer treatments would be effective over the long term. Suzy's doctors tried to talk her out of a mastectomy because they felt that they could remove the tumor and rule out recurrence with radiation. Suzy was uneasy with this approach. "It would have just been too stressful for me to wonder if it's all gone and is the radiation really killing it?" Concern about the efficacy of radiation or chemotherapy and subsequent side effects was widespread amongst study participants. For these women, mastectomies produced far less anxiety than a lumpectomy along with radiation and/or chemotherapy. Linda wanted medical intervention to be as short term as possible. Speaking about her options of lumpectomy and radiation or a mastectomy, she said:

> I wanted to avoid it [radiation] at all costs and [my surgeon] said, “If you have a mastectomy you won't have to have radiation.” I actually had to go home and let it register and call her back and say, “Did I hear you correctly, that if I have a mastectomy I won't have to have radiation?” And she said “Yes,” and I said “Sign me up; it's going to be a double.”

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[1] These scans can be time consuming and expensive. Additionally, not all imaging facilities are equipped with proper MRI tables for breast scans. Additionally, these tests are not always accurate. They can both miss cancers or lead to a diagnosis when cancer is not actually present.

Rachel also expressed concern for the potential side effects of non-surgical treatments, though she ultimately did undergo chemotherapy. Samantha, too, worried about the future health consequences of radiation, such as the possibility of developing other forms of cancer. She had a long family history of various cancers and wanted to ensure that her decisions about breast cancer did not impact the treatment of any future cancer. Samantha's concern stemmed from the fact that tissue can only undergo radiation once. If a woman had radiation therapy and her cancer returned in the same area, she would not be able to have radiation again and would likely end up having a mastectomy. When she did contract breast cancer a second time, she expressed relief that she had not undergone radiation treatment previously. In the first bout with breast cancer, she decided against radiation because "down the road I might need it and you can't radiate the same area twice." She also expressed concerns about chemotherapy because she'd "seen what hell it's done to people." Her overall approach to her first cancer was aggressively non-invasive. During the second occurrence, Samantha chose mastectomy in order to avoid radiation, though her qualms with radiation had less to do with side effects than with the logistical difficulties she faced in getting to the clinic for treatment on a regular basis.

Decisions about treatment can be complicated by a lack of certainty on the part of medical providers. In Alison's experience, the medical recommendations weren't clear. She recalls that her breast surgeon "initially wasn't sure if a lumpectomy would be adequate." The range of medical options and the occasional difficulty in assessing the full extent of breast cancer can create what seems to patients to be considerable ambivalence about the most effective treatments. What women in this study tended to express was their feeling that a mastectomy, either unilateral or bilateral, was the surest means to prevent future risk of recurrence or a new diagnosis.

When Edie was first diagnosed with breast cancer, her surgeon was unequivocally negative on the issue of bilateral mastectomies. When Edie requested the procedure, she recalls that her surgeon said, “No, I won't because there's nothing wrong with the other one. It's healthy. I'll send you for extra testing to make sure but I'm certain it's benign and I refuse to cut off a healthy body part." She sought a second opinion, and found a surgeon willing to do the procedure if that was her choice. Edie's first surgeon relied on the medical narrative of risk. Because the surgeon believed that the healthy breast was unlikely to develop cancer, he refused surgery. For Edie, the potential for cancer and the emotional risks associated with surveillance were too great *not* to have a bilateral mastectomy.

Rachel's doctors tried to steer her away from a mastectomy after her breast cancer diagnosis. Her doctors told her, "You don't need to do that. We don't like the idea of doing that, but if it's your wish we will do it." She added, "The response was ‘It's not necessary. You have a small early stage breast cancer. It's not necessary.’" Several participants disclosed the reticence of their surgeons when women brought up prophylactic mastectomies. Colleen's surgeon urged caution in making this decision. "I had brought up mastectomy to my surgeon a few times and her position was, ‘I understand why you're interested in this, but it's not really necessary. I'm not going to talk you out of it if it's something you really want to do, but I want you to think about it.’" Women commonly described their surgeon's response in these terms. Physicians are basing their recommendations on data from medical studies suggesting that prophylactic mastectomies do not significantly reduce cancer risk but many women want the surgery anyway.

For the BRCA-positive participants, future cancer risk was very real and recognized by physicians. Women in the general American population have about a 12% lifetime risk of breast cancer (National Cancer Institute 2014). Studies vary as to the exact lifetime risk for women with

BRCA mutations, but researchers assess the risk as significantly higher than that of the general population. The National Cancer Institute reports that women with the BRCA 1 mutation have a 55-65% lifetime risk of breast cancer and women with the BRCA 2 mutation have a 45% chance of developing breast cancer by age 70 (National Cancer Institute 2014). Other studies suggest even higher lifetime risks ranging from 45% for women with BRCA2 (Antoniou et al. 2003) to 82% if the woman is of Ashkenazi Jewish heritage (King et al. 2003). In their meta-analysis of literature on lifetime breast cancer risk in BRCA positive patients, public health researchers Sining Chen and Giovanni Parmigiani reported an average 64% lifetime risk for women with BRCA 1 and 56% for women with BRCA 2 (2007). In addition to BRCA there are a range of other genetic conditions and medical conditions that increase a woman's risk for breast cancer and can influence her physician's surgical recommendations.

Sociologist Sharlene Hesse-Biber is particularly critical of the ways in which the developers of BRCA testing procedures capitalized on this fear (2014). She argues that especially for those with positive BRCA tests, the genetic testing industry has waged a massive campaign that encourages women to feel fear and anxiety about BRCA and to overestimate their medical risks. Hesse-Biber is not specifically questioning the fear response, simply the ways in which biomedical companies capitalized on it. Medical professionals have, perhaps, gone too far in minimizing the importance of fear in a patient's consideration of treatment options. Fear is significant in this process not just as a personal emotion, but as a cultural phenomenon. Sociologist Andrew Tudor argues that fear is not only emotional but also cultural. According to Tudor, "fear is embedded in a complex of physical, psychological, social and cultural relations." His analysis shows that fear is a matter of perception and as such is socially mediated. The type of studies that medical professionals rely on for data to guide evidence-based medicine are not equipped to explore fear in this way. Instead, such studies are used by medical professionals to discount fear by "proving" that the risks of cancer are low enough not to cause concern. Yet the fear that women feel when facing breast cancer and BRCA is embedded in a cultural system that marks breast cancer as the ultimate threat to health, life, and femininity. Cancer in general is implicated in a "war" waged by the federal government, biomedical researchers, and women themselves.[2] In other words, the fear described by women in this study and the fear upon which biomedical researchers focus are not exactly the same thing. Additionally, fear is implicated in a struggle for power. Valérie de Courville Nicol (2011) asks "how do emotions fuel and structure agency, and more particularly the exercise of power? … How do emotions promote social conformity and condition social change?" These questions are deeply important to the tension between medical standards and patient desires for prophylactic mastectomies. In requesting prophylactic mastectomies, patients are engaged in the classic sociological structure versus agency debate. In making this choice they confront the medical institution and the gender structure by failing to conform to medical standards of care and by essentially questioning the physicality demanded by norms of femininity. This failure to conform to medical and gender norms suggests that fear in this situation is a potential catalyst for changes to the status quo. The decisions of women to request prophylactic mastectomies and the willingness (or lack thereof) of physicians to perform the procedure is wrapped up in a culture of cancer fear and cultural expectations of gender that are not necessarily aligned.

Health risks were a very real concern for all women who participated in this research. Emily justified her decision to get tested for BRCA in terms of risk management. She stated,

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[2] Cancer became intensely visible with Richard Nixon's 1971 declaration of a "war on cancer." In this framing the medical community, the government, and individual citizens became entrenched in an ongoing battle against disease.

"The reason I wanted to know in the first place was [with BRCA] there's something you can do. …Once I found out that I was positive it was a question of do I want to go through regular screenings every six months?" She anticipated abnormal screening results and wondered, "If they see any tiny little thing that looks abnormal they still have to investigate it. So at that point they would do a needle biopsy[3] and you would wait around and find out if you have cancer or not." The option to have a bilateral mastectomy meant that she could proactively do something to reduce her breast cancer risk and avoid unnecessary stress in the future. Michelle, also BRCA positive, echoed this sentiment. When her doctor conveyed to her that her risk of breast cancer was 80-90%, she said, "I kind of decided right then and there that I was going to have the mastectomy, no questions asked, sooner than later. I felt at that moment like I could lose my breasts and still have a good life. I could reduce a lot of risk and still have a good quality of life." Rachel also described facing the possibility of increased surveillance. "My thought process was just based out of fear. I didn't want to have that worry of it coming back. I would constantly be obsessing over lumps." Katie, a BRCA positive participant, neatly summarizes the general sentiment of BRAC-positive women: "I had this real love/hate relationship with my breasts. I loved them but I was afraid of them. I was afraid of what they could do. I was afraid of what was inside of them." For Katie, as for many women in this study, fear of cancer trumps the love of one's breasts when it comes to managing cancer risk. While the decision to have bilateral mastectomy was often emotionally difficult, the fear of cancer and ultimately death were critical in women's decisions.

While biomedical research tends to define risks in the context of breast cancer only in terms of medical outcomes, the women I interviewed include emotional risks in their decision-

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[3] Needle biopsy is a surgical procedure done under local anesthesia. A hollow needle is inserted into suspicious tissue in order to remove a sample that is then examined by a pathologist.

making. Physicians are not uniformly averse to making surgical decisions based on patient anxiety however. Standards of gynecological care for transgender men, for example, suggest that if patient anxiety about the exam is too great then a hysterectomy is warranted. In the case of transgender men, it may be that a perfectly healthy and functional organ is removed for the sole purpose of diminishing emotional strain that prevents an individual from seeking care. Such a surgery also continues to alter the patient's body in a way that aligns with the patient's gender identity. In other words, a trans male body without a uterus is comprehensible to some in the medical community. Cisgender women who identify as women and who wish to remove their breasts are unintelligible for some physicians. Both trans men and cis women in these instances are asking doctors to remove healthy tissue. It is unclear whether cis women avoid screenings due to this anxiety, thus the extent of emotional upheaval may be invisible to medical providers. Aside from the visibility of anxiety, the key difference lies in the perception of patient gender.

Parenting Concerns

Some participants referenced their responsibilities as parents as motivation for choosing mastectomies. In some cases, parental responsibilities were closely linked to a fear of future health risks. Rachel's role as a mother enhanced her concerns about future risks: "when I was diagnosed I chose to have a mastectomy over a lumpectomy because I was [in my thirties], I still had young children, I was very afraid." This fear is rooted in the possibility of death and an inability to care for one's children. Kate stated, "It goes back to the cancer equals death, I don't want to die. I need to get the cancer out of my body. I had two young children at the time. I was very focused on, you know, wanting to live as long as possible… I would like to live and I would like to have my children under my care." Colleen's knowledge that she wanted to have children and her oncologist's support were crucial in her decision to have a bilateral mastectomy.

> The new oncologist I was referred to was a woman and I feel like she was maybe a little more sympathetic than the men I had seen. She actually brought mastectomy up when I met with her for the first time. She was like; if I was in your position I would do it in a heartbeat. She said, well you just got married, you can think about it now or you can think about doing it after you have children. That was like, oh wow, ok. I didn't really think about the timing for the kids and yeah if I want to have kids, well, I don't want to do it after I have kids. First of all, another two more years that I have to worry, second of all, I'm going to have this major surgery with, you know, a kid or two running around? That felt horrible, so my decision was alright, I want to do it and let’s do it now. I want to get this out of the way. I want to just go on with my life, then I can think about having kids.

Explicit in Colleen's statement is her concern for parenting young children while recovering from surgery. Although with her particular type of cancer mastectomy was a choice, the potential of a recurrence and eventual surgery prompted her to choose the medical intervention that she felt gave her the best opportunity for the life she envisioned for herself.

The fear of not being around to care for one's children was also a strong motivator for women with BRCA. After growing up and watching several generations of women in her family die after being diagnosed with breast cancer, Katie strongly believed that she "did not want another woman raising my children" and that she "wanted my children to see that a woman in her family could grow old…. It really felt like, knowing the fear I had lived with, I didn't want my children to live with that fear." A BRCA diagnosis can include not only a future risk of breast cancer but also a risk of ovarian and uterine cancers, although women are generally advised to delay hysterectomies due to the hormonal changes brought on by the surgery. For Michelle the desire to have children and to have a long life in which to parent them directly impacted her decisions about surgery. Upon receiving her diagnosis Michelle made a quick decision.

> I kind of decided right then and there, going to have the mastectomy, no questions asked, sooner than later. I felt at that moment like I could lose my breasts and still have a good life. I could reduce a lot of risk and still have a really good quality of life. … I want to have kids; I want to have a family someday. I can have kids and I can do all the things I want to do without my boobs.

The one thing that Michelle would not be able to do after a bilateral mastectomy is breastfeed her future children. Experiences of breastfeeding and thoughts about the ability to breastfeed future children figured prominently in the decisions of many women. Many women who had breastfed felt that this experience allowed them to choose mastectomies because they felt their breasts had served their purpose. At the beginning of this chapter, I quoted Karen's positive feelings towards her breasts due in part to her success as a breastfeeding mother. She was able to let go of her breasts because breastfeeding had been successful and she wasn't planning any other pregnancies. For Fran, breastfeeding and her decision prior to diagnosis not to have more children figured critically in her decision regarding mastectomy.

> In fact, I'm sure that if I had been younger and had been planning on having another child, then I would not have had the mastectomy. … it's a great pleasure to feed a child with your breast. It's an extraordinary pleasure and one knows that it's good for the child. On both of those accounts I would've done what I could to save the breast if I'd been planning on another child.

Liz also did not plan to have more children at the time of her breast cancer diagnosis. Her positive experience breastfeeding her second child was significant in her decision to pursue bilateral mastectomy. Her first attempt at breastfeeding her oldest child was painful and unsuccessful. With her second child, Liz breastfed with ease and remembered the time leading up to her mastectomy.

> I remember a couple nights waking up holding my breasts, and I feel like that was more of me saying goodbye and thank you but it didn't really make me stop. I knew I was done having kids, so I felt like they had served their purpose in my life… – I never saw my identity in my breasts so I never felt that that piece of it – it was they served their purpose as me – for me as a mom and I don't need them anymore.

While the positive experience of breastfeeding enabled many women to let go of their breasts, it caused sadness in others. For Karen, breastfeeding was a particularly special bond with her youngest son.

> Whenever people would [ask], how are you feeling about surgery coming up or whatever, I could be like oh, you know what, I'm okay with it. … I mean I did some minimizing of it, like, whatever, my breast betrayed me, let's get rid of it, the other one's guilty by association, so, you know, be gone with them. But if somebody asked me something around, like, the breast feeding issue or anything, then that was like a trigger for tears and – yeah, a lot of tears.

Breastfeeding is growing in importance for many mothers in the US. In 2006, the American Academy of Pediatrics (AAP) and the American College of Obstetrics and Gynecology (ACOG) jointly published *Breastfeeding Handbook for Physicians* in response to research finding that "only 71% of women ever start breastfeeding" (ACOG 2006). The US Department of Health and Human Services also launched a campaign at that time to increase the incidence of women breastfeeding to 75% and to increase rates of prolonged breastfeeding (past 6 months) to 50% (ACOG 2006). The AAP released an updated policy statement on breastfeeding in which they argue that "breastfeeding and human milk are the normative standards for infant feeding and nutrition" (2012). The policy statement goes on to identify disparities in breastfeeding utilization and the benefits of breastfeeding to mothers and children. The policy ends with a recommendation that mothers exclusively breastfeed their children for six months, and continue to do so, along with introducing solids, for at least one year. Following these statements, the AAP indicates various clinical practices that should be encouraged by physicians in order to promote breastfeeding. As a result of these efforts and those of breastfeeding advocacy groups such as the La Leche League, breastfeeding has achieved a strong cultural presence, despite many controversies over public breastfeeding (Wallace 2014). Issues of visibility aside, breastfeeding is framed as an essential experience for both mother and child.

The possibility that a woman will be unable to participate in this purportedly magical and healthful experience presented difficulties for some young women with a BRCA diagnosis. Emily characterized this dilemma as containing "a lot of emotional attachment involved in that because it's a rite of passage as a mother" and went on to remember being a small child when her mother was diagnosed with breast cancer.

> I was envisioning myself potentially having a child who is one, two, three years old then potentially getting breast cancer. And I just couldn't justify that in my head, the possibility of having children and then potentially getting sick and dying. (laughs) I would rather – much rather you know, forego the cosmetic – the cosmetic issues that are involved in having a mastectomy and you know, not be able to breast feed but then be there for my children and see them grow up. So, you know, I'd rather live.

Michelle also expressed sadness at the idea of losing the ability to breastfeed. At the time of our interview several of her friends were pregnant or new moms and often discussed breastfeeding and pumping. While Michelle told me that this "sounds like a huge pain in the ass," she also felt sadness. "I'm kind of sad I'm not going to be able to do it. It seems like a really great special bonding time with your baby and nutritionally you pass so many good things on to your baby." She went on to say:

> I know there are tons of people that are – that don't breastfeed and their babies grow up beautifully and healthy and they do have bonding time and all this stuff. So it's probably, you know, it's going to be fine that I'm not going to be able to do it but it does kind of bum me out a little bit that I never even get to experience and I feel like that's just a – a maternal thing. A special bonding maternal thing that I'm not going to get to experience.

Breastfeeding can be a complicated issue. For Sally, her breasts were a constant source of discomfort (due to large size) except for when they were used for breastfeeding. The act of breastfeeding signified the usefulness of breasts and also a sense of connection to one's children. The sense that breasts had fulfilled their purpose in sustaining the life of infants allowed some women to let them go while the connection to one's children made a mastectomy decision somewhat more difficult, particularly if a woman had not yet had children but planned to in the future.

Several women underwent mastectomies while their children or grandchildren were quite young. While breastfeeding was no longer a concern for them, the reactions of these children were important to women who chose mastectomy. In general, these women had a very matter of fact approach to explaining their surgeries to the children in their lives. Ellen's grandchildren began calling her "Grandma Booby" after she "got [her] boobs cut off." Her youngest grandchild, who was an infant at the time of surgery, later asked her, "Well, why don't you have boobies?" Ellen responded with, "because they got sick and the doctor had to take them away." This type of simple and straightforward approach to explaining mastectomy was mirrored by how women felt their children responded to their surgeries. Kate explained, "I'm the only body that my daughters know. This is it. I mean this is who I am. I haven't moved into any category that would be like, oh mom, your body is embarrassing because of breast cancer." Kate's now teenage daughters have grown up while their mother had a mastectomy and complications from reconstruction. Now that she lives flat, she feels that her breasts are a non-issue with her kids.

Children can also help to normalize a woman's body after surgery. Judy has an open door policy with her son where he is able to come into her room under any circumstances. A few weeks after her mastectomies, her son came into her room while she was undressing.

> [My son] came in and I said, stop! And he goes what? And I said, I’m ready to pull my shirt above my head and put my pajamas on. And he comes in the rest of the way and he says okay, so? And I said well, you’re going to see scars if you don’t turn around. He goes well, I don’t care. Scars are scars. Alright, so I flip my top up and I turn towards him and he goes yeah, what of it? They’re scars. Okay. Put my pajamas on and said alright, what else did you want and we had an entire conversation afterwards. Never blinked an eye. Never batted, flinched, nothing, whereas my husband about puked.

While Judy's husband struggled with her recovering body, her son acted as if everything was fine. Fran's son was immediately very supportive of her mastectomies and decision to remain flat. According to Fran, "He's really great. He said, ‘so mom, you'll be kind of like a Minotaur. You'll be like, girl on the bottom, boy on top.’" While not every woman would be pleased to be characterized as a mythological creature, Fran understood her son's comment to be one of acceptance and unquestioning support for what his mom intended to do.

The comment of Fran’s son that she’d be both a girl and a boy is crucial to understanding some of the tension underlying prophylactic mastectomies. Breast cancer is culturally understood not only as a threat to the health and life of a woman, but also to femininity. Cancer threatens the individual femininity of women by occurring in a body part deeply connected to motherhood and sexuality, both of which are intrinsically tied to normative femininity. Breast cancer also threatens femininity on a cultural level. As a society, we invest vast sums of money into breast cancer research in order to “Save the Ta Tas.” Clearly, breasts are of national cultural concern, not simply of interest to individual women. Mixing boy and girl, masculinity and femininity, in a single body is uncomfortable culturally. Given that gender is culturally defined relationally male and female, masculine and feminine are placed in opposition (see Connell 1987). Troubling this separation can create social anxieties (see Westbrook and Schilt 2014). The emphasis on saving breasts through increased awareness of breast cancer and the importance of regular screenings, as well as on the biomedical insistence that lumpectomies and radiation are just as good as mastectomies for treating cancer lend a certain sacredness to breasts that is embedded in cultural ideals of what a woman’s body should be. Additionally, when cisgender women blur the bodily lines between man and woman by altering their bodies through mastectomy, they inadvertently call into question the assumption “that there are certain bodies, behaviors, personality traits, and desires that neatly match up to one or the other [gender] category” (Schippers 2007, 89-90).

The issue of authenticity and comfort also permeated Sally's understanding of her daughter's reaction to the bilateral mastectomy. Sally described her previously large breasts as negatively impacting her happiness. Now, she says that her daughter "sees me being happy because I don't have these giant boobs. She sees me being able to be more free in activities and just at home playing with her." Although breasts can be important to a woman’s identity, they can also get in the way. Several women described the difficulty they had with what they considered over-large breasts. Athletes in particular described how their breasts got in the way of physical pursuits. For Sally, it was more important that her daughter see a woman able to move freely in the world than to see her mother with breasts. The physical constraints placed on women is a cornerstone of feminist theories of the body (see, for example, Young 1980 and 2005). Many of the women I interviewed believed in feminist ideals of empowerment. Physical freedom of movement was important to these women. In some cases, like for Sally, removing breasts meant greater physical freedom and this was seen as valuable in setting standards for young women.

As supportive as many children were of their mothers and grandmothers, others found the post-mastectomy period emotionally trying. Karen's youngest son had a particularly difficult time with her decision to live flat as he was still nursing until shortly before her diagnosis.

> When we're snuggling, getting ready for bed, sometimes he'll say something like, I really liked the milk I used to drink from your breasts or something, and I'll say oh, yeah, you know, I really enjoyed that. That was a good experience for us. … So he'll just say something small like that on occasion, or he'll say remember when you were squishy? You know, like, right after my surgery he was calling my chest "no-boobs." And he would be like; I don't like your no-boobs. I mean it hurt my feelings terribly. I mean he was – you know, he was just about to turn three when I had the mastectomies and he's like I don't like your no-boobs, and,

> you know, you need to get them back. And you need to grow them back and I was like no, I'm not going to grow them back, this is how they are going to be.

Even though Karen's son lamented the loss of her breasts, it was her older son's fears that she might die that produced greater concern for her.

> My older son struggled a lot and continues to struggle a lot. My father-in-law died of prostate cancer about a month before I was diagnosed and so he still says things like, Grandpa had cancer. Grandpa died of cancer. Mommy had cancer. And he's just, like, waiting. … And I'm like, not everybody who gets cancer dies from cancer, but he has anxiety about it. My husband travels a lot and whenever he's gone; my son just has massive anxiety. I talked to him about it, like when Daddy would come and go [before the diagnosis] you were fine and I ask him why he's upset. And he's just told me straight up, well that was before you had cancer. What happens if Daddy is away and you get cancer?

Karen's younger son's sadness about her breasts was overshadowed by her older son's concerns that she could die. Similar to Karen, many women I interviewed understood mastectomy to be the best insurance against dying from cancer, thus allowing them to be fully present as parents.

The relationship between breast cancer and parenting involves a range of emotions. Women in this study feared death and they were anxious about the impacts that a future cancer might have not only on their bodies but on their families. Breasts, as physical markers of motherhood and femininity were often very significant to women, being a present parent was far more important. Children sometimes helped to normalize a woman’s new body when intimate partners struggled. Yet women explained that children also expressed fear and anxiety about the health of their mothers and grandmothers sometimes through talk of breasts as they used to be. For both BRCA positive women and women with breast cancer, they believed a long life without the anxiety of cancer was worth the physical sacrifice of breasts in order to be fully present for their existing or future children. While breasts are deeply connected to mothering, one can mother effectively without breasts.

The concerns of women as current and future parents is also embedded in a culture of fear and biocitizenship about which Hesse-Biber is skeptical. She argues that the culture of fear surrounding breast cancer and BRCA in particular hinge on notions of patient self-empowerment that include an imperative for patients "to be proactive for their health and their family's health" (Hesse-Biber 2014, 25). What Hesse-Biber refers to is the creation of "biocitizens;" individuals who have a set of biological responsibilities regarding health behaviors and education (Rose and Novas 2005). As such, it is not just quality of life that drives women to choose bilateral mastectomies. When women describe minimizing their future health risks through bilateral mastectomies they are acting in accord with the imperatives of biocitizenship to "control, manage, engineer, reshape and modulate the very vital capacities of human beings as living creatures" (Rose 2007, 11).

In this new cultural climate, health is "more than simply guarding against disease" (Moore 2010, 112). Health is about self-presentation, identity, consumption, morality, and social membership. This broad understanding of health is fundamental to women's choices about bilateral mastectomies. The medical community's discounting of quality of life factors ignores the myriad components of health in favor of a narrow biomedical definition. I do not contend, however, that medical practitioners are necessarily insensitive to the wishes of their patients. Rather, the differing medical opinions and general medical concern about prophylactic mastectomy, the variation in acceptability for bilateral versus contralateral mastectomy, and the tensions that women experience as they determine what degree of surgical intervention they desire are embedded within normative expectations about female bodies.

Intimate Partners and Sexuality

Women generally described their spouses and partners as supportive of their decision to undergo mastectomies, often because intimate partners shared women's concerns about future cancer risk and death. Alyssa told me that her husband "lost both of his parents when he was young so he was absolutely terrified that he was also going to lose his wife." As a result, he encouraged her to have a bilateral mastectomy. Similarly, Karen's husband told her that "any risk at all" was unacceptable, thus supporting her decision to have a bilateral mastectomy. In other cases, watching their loved one experience the anxiety of medical testing led spouses and significant others to support mastectomy. Edie noted that everyone in her life was "supportive for the same reason, that they had seen how much anxiety it caused me for so long." Her husband, "ultimately really realized how much anxiety [another breast cancer diagnosis] caused me and so he's been very supportive." Colleen's husband also responded to her anxiety regarding a future recurrence. While he was initially cautious about the idea, Colleen maintained that "ultimately he really recognized how much anxiety it caused me and so he's been very supportive" even though he "probably had a little more hesitation than I did."

Ellen described her husband as uniformly supportive. She remembered his response as, "Whatever we have to do we're going to do…. You're my wife. I love you and boobs aren't going to make a difference." This was a fairly standard response that women reported from their intimate partners. Despite the unwavering support of their intimate partners, however, many women felt concerned about how their scars would impact the other person and their own sense of sexuality. Several women mentioned that their breasts were their intimate partner's favorite body part. Samantha was very careful to gauge her husband's comfort level.

> I think it also helped a lot that we talked about it beforehand. How he might feel and afterwards showing him the scars, showing him the bandage and then the scar

> and watching his face and asking him how do you feel about this? And how do you feel about me having the other side off? And, after surgery, he saw the bandage. And he looked very calm and he said I'm okay with it. Are you in pain? Are you okay?

Ultimately, Samantha's husband main concern was with her own comfort and happiness. According to Samantha, "You couldn't ask for better than that." Their openness in discussing the changes in her body has, in her opinion, strengthened their relationship.

> It's opened him up, which in a way makes me feel even stronger towards him if that makes any sense. He's showing that he's baring what we sometimes term as a vulnerable side to us, exposing our deepest thoughts. He's growing more and more comfortable with that.

A shift to greater emotional intimacy was expressed by several women. Yet the physical changes sometimes remained difficult to navigate. Judy felt that her husband struggled deeply with the scars. She reported that although he initially indicated to her that he didn't want to see her chest, eventually Judy decided that it was important that he saw. "I pulled my shirt up and he goes, 'oh my God, don't show me that again.' He's never seen them since." Because Judy didn't want to talk about it further, it was unclear in our interview what she felt was the source of her husband's discomfort. The potential for this type of reaction did make several women hesitate in their decision to have a mastectomy.

A key contributor to women's concerns about their partners was sexuality. For many women, their breasts were integral to sexual intimacy. As Karen explained:

> I mean, it's a sexual organ that you don't have any more. You just lost a major erogenous zone which is weird. … I mean of course it would be a much bigger problem, in a practical sense, if you lost an arm or a leg but it is still a body part that serves a certain function and that function is no longer there. I mean, you regain some feeling in the chest, but it's not the same kind of feeling obviously. (laughs) And it's also not complete; I mean there's still like a band right across the scar, that's basically numb. So that is weird.

The loss of this sexual function was upsetting for many women, but was a worthwhile sacrifice in light of their concerns about future health risks. Still, feeling sexy and engaging in sexual acts proved difficult for some women both before and after surgery.

Karen's struggles with intimacy began prior to her surgery. She initially intended to have a single mastectomy because of the sexual importance she attributed to her breasts. This feeling changed in the time after her diagnosis.

> Every time my husband touched my breasts I would cry. Our entire relationship became breastless before I lost the breasts, so it was like whatever six or seven months of intimacy that didn't include them because that would take me out of the moment and make me cry. I'm like it would have been better if we could have like bound them up and put them away so that we could enjoy ourselves. So it became a much easier decision. Initially I wanted to keep the other breast, I'd say, primarily for sex. By the time I made it through all that other stuff it was like you know what? It is just not that important as I thought it was.

Being touched after mastectomy was difficult for many women. After her bilateral mastectomy for BRCA, Michelle lamented the impact on her sexuality.

> Intimately it sucks. Like it's totally lame. I used to have sensitive boobs. I don't like when people touch my chest at all now. I think a guy kind of gets the point after a few dates when I'm like, don't touch my chest or something. Or we'll make out or something but I insist on leaving my bra on, I will not take my bra off. I think a guy kind of gets the point. And so, inevitably, you know, after four, five, six dates, whatever it is, it comes up.

The physical changes brought about by mastectomy are undoubtedly important to individual’s intimate relationships. Given the importance of heterosexuality to the gender order at large, these individual struggles with sexuality indicate a greater social significance to the recent trends towards bilateral mastectomies. The choice to remove one’s breasts alters the symbolic meaning of heterosexuality to the gender system. Schippers explains that heterosexual desire is “the basis of the *difference between and complementarity of* femininity and masculinity” (2007, 91 emphasis in original). As Fran’s son explained, when she removed her breasts she became a boy and a girl. That is, bilateral mastectomy took away the difference and complementarity that is produced by and integral to heterosexual desire and is fundamental to a gender system based on hierarchical relationships.

While some women considered the sexual impacts of surgery well in advance, Liz reported being particularly surprised by her sexual reaction.

> I had not considered the sexual aspect of it; I hadn't considered that I would be self-conscious about it. That took me by surprise (laughs) because I just had never identified with my breasts and then all of a sudden I was self-conscious about it and I was like why am I self-conscious about it?

For Liz, being touched meant that she couldn't ignore her experience with cancer. Every time her husband touched her chest, it was a reminder of what she had gone through and brought up her concerns about how her husband felt about her body. None of the women in this study expressed any regret about their decision to have bilateral mastectomy. Their commitment to this choice did not make the impact on their sexuality any easier to handle. Sexiness is thus partially defined by a woman's sense of how her body looks both to herself and to her partner. Perhaps more important, however, is the role of touch in relation to breasts. Prior to surgery, the sensation of touch could be emotionally painful even if the physical sensation wasn't. After surgery women lost physical sensation and had to cope with what that meant for their experience of physical intimacy.

Concern about their male partner's reactions to the loss of breasts was fairly common. Many women mentioned that their male partners eroticized their breasts. Ellen's concerns were compounded by her recent hysterectomy.

> My main concern through all this was, like, I didn't want to be like he's making love to another man. I had a hysterectomy a year after the mastectomies which put me in a sexual quandary. I didn't know if I was a man. Am I a man, am I a woman, what am I? I don't know what I am. I was questioning who I was because I had no female parts anymore. And no desire for sex, either.

Losing her breasts, uterus, and ovaries significantly impacted Ellen's gender identity and her interest in sex. She had always liked her breasts and described them as "cute and perky." Her breasts were an important part of her identity and losing them along with other parts that she linked to her gender identity and sexuality caused her to question how her husband perceived her. In Jean Elson's study of women who have had hysterectomies, she argues that, "the ability to feel sexually attractive is an important component of self-identification for many contemporary women, as is the ability to feel sexual desire and erotic pleasure" (2004, 123-124). Ellen's statement raises not only the issue of sexual function, but also that of gender identity and sexuality. When Ellen questions her identity, she is implying that this identity is a combination of gender (the body parts) and her heterosexuality. Without the parts that make her female, her sexuality no longer makes sense in relation to her male husband. The relationality of both gender and sexuality are clear in her statements. When her gender is no longer obviously female to her, then the heterosexuality of both partners becomes questionable. Typically, a man’s heterosexuality is socially questioned because of his behaviors; his failure to “do masculinity.” Ellen suggests a deeper relational context in which a heterosexual man’s identity can become questionable through his partnership with a woman who chooses to live flat and thus fails to “do femininity.”

In addition to the impact on personal sexuality and the relationship with an intimate partner, Ellen’s sexual quandary expresses the ways in which a person’s sense of being a man or being a woman can be challenged by physical changes. Commonsense notions of gender identity include a sense that we each have a core gender identity. This is the logic underlying the “wrong body” narrative of transgender people. Ellen’s statement above suggests that instead of a core gender identity that is unalterable, this identity can be linked to secondary sex characteristics.

Ellen questioned who she was because she had no female parts. Ellen’s experience is almost the inverse of the mainstream transgender narrative. The visibility of gender matters not only for social interactions but also for personal identity.

While losing one's breasts does not necessarily obstruct sexual interest it can be difficult for many women to “feel sexy” after bilateral mastectomy. Maggie attributes this to her own reaction to surgery rather than to the reaction of her wife. "I think I feel more damaged than she sees me, just because of the scars. I have a hard time feeling sexy. I'm working on it (laughs)." Maggie's wife participated in all the decision-making surrounding Maggie's breast cancer diagnosis and remained consistently supportive. Despite this type of support, many women remained worried about how to appear sexy to their partners. Nicole's main concern about mastectomy was "feeling like I wasn't sexually attractive to my husband." Even though he made an effort to reassure her, Nicole felt that "I still want to be sexy in his eyes. I want the sexual attraction to still be there."

Catherine actively dealt with her concerns about being sexy by deciding to remain nude while at home at all times in order to help her husband become comfortable with her scars.

> I really do think my body is badass, but it's been hard to settle into the changes. My husband was really having a hard time and I just decided, without even really telling him that I was going to be nude around the house as often as possible. And it really helped me to see the beauty of my person and I believe it helped him to accept the changes. … My thing is; how do we make this beautiful? I would love to see a bustier that just comes slightly out and away from the body and sort of just gives a little gentle peek of the scars. Like there is nothing to hide here. It's only beautiful. Unless of course we decide to buy into the idea that we are our breasts. And I can't be my breasts anymore because my breasts had to go (laughs). So I don’t want to. I want to figure out a way to make this sexy, desirable.

Catherine's linkage of beauty and sexiness points to a general consideration among women who choose mastectomies to attend to their own aesthetic sensibilities. Although Catherine's decision to be nude as often as possible was partially for the benefit of her husband, she was also fundamentally concerned with her own impression of the beauty of her body. As with Maggie, what is at stake here is a woman's ability to see her body as beautiful or sexy after a mastectomy. Sexiness is not limited to a woman's self-image, however. The impact on intimate partners, combined with a woman's sense of her own sexiness, were both important considerations as women navigated their self-image after choosing bilateral mastectomy.

Many women were concerned about their partner's reaction to the mastectomized body. Men with breast cancer, in contrast, told me that their partners were unequivocally supportive while women wrestled with the impact of their decision on their partner. It is possible that this is rooted in the matter of choice. Men had mastectomies as a matter of medical necessity, whereas women who have bilateral mastectomies generally choose to alter their bodies. Cis women and trans men are united by the discourse of choice. Both choose to do things to their bodies that run counter to social and medical expectations. Cisgender men with breast cancer are responding to an accident of nature that is beyond their control. Cis men *have* to undergo mastectomies while cis women and trans men *choose* to alter their bodies, thus baffling certain medical providers. Medical providers react to these choices by recommending further alterations to the body (breast reconstruction after mastectomy for cis women and hysterectomy for trans men) in order to bring these wrong bodies back into alignment with the gender norms that drive medical care.

Aesthetics and Self-Image

Aesthetic considerations and self-image figured prominently in women's decisions to undergo bilateral mastectomies. Maggie, a competitive athlete, never liked her breasts and found them to be discordant with her identity as genderqueer. As soon as she was diagnosed she knew that she wanted her breasts removed.

> The second they told me that there would be a surgical plan, I said, "Well then I'm going to do a bilateral mastectomy." And to be 100 percent honest I never really

> like my boobs anyway. Never liked having boobs, and I had *boobs*. … [The] surgeons didn't question me at all. They were like, "Okay then, that's totally appropriate" and they moved on. … I think that I had a relatively unique experience. I talk to other people and the sheer number of people who tell me that there was resistance to doing the bilateral because the other breast is healthy. [My doctors] were clearly able to meet me where I was and respect me as the person that I presented myself to be.

Frustration at having large breasts prior to diagnosis was frequently mentioned by women as a motivating factor in the decision to have bilateral mastectomy, even for women who did not identify as genderqueer. Linda had considered breast reduction prior to mastectomy.

> I was extremely large-breasted before this. (Laughs) You're going to think I'm lying but the thing is I was wearing a 40M bra, as in Mary, and falling out of it. I had girls everywhere. … I hated these huge breasts. I have looked at reduction, I thought about reduction every single solitary day of my life.

For many women, large breasts negatively impacted their quality of life prior to breast cancer and BRCA. Large breasts were described by participants as limiting multiple aspects of everyday life from the type of activities a woman could comfortably pursue to the kinds of clothes she could wear. Jody had also considered a breast reduction prior to a positive BRCA diagnosis, saying "[I had] never really been happy with my breasts." Sally, also BRCA positive, described the difficulty of having breasts in her pursuits as a high school and college athlete, "[my breasts] were just too big for me, for my frame. They got in my way."

Aside from size, the appearance of pre-diagnosis breasts was distressing for some women. Judy described a painful adolescence and young adulthood marred by extremely large and lopsided breasts that grew at different rates.

> When I started going through puberty, my breasts were not growing at the same rate. And every woman's breasts are slightly different in size, okay? None of us have perfectly spherical symmetric breasts. Mine, however, was the difference between probably a 42C versus a 38B type thing. There was at least a two size difference. … Gym class was torture. High school gym class back in the 70's when you all had to take showers together. Every other girl in the locker room has got these perky little cute boobs. I used to take my towel into the shower with me

> and open it up and kind of, you know, sort of like you’re just standing there with your towel half mast, so to speak. You’re blocking everyone else’s view but you actually get the spray coming down on the front of you yet. You know, your towel’s not getting wet but nobody else can see you. But then somehow or another somebody found out and then it spread like wildfire through the school. So, I wouldn’t get directly teased by it, but there was a certain group of boys that every time one of them went down the hallway past me or something they would make a noise loud enough for everybody else to hear. And everybody that knew what that noise was knew that it was about me. So, that was extremely humiliating.

Although large breasts are portrayed in popular culture as aesthetically pleasing and desirable, in the everyday lives of women they are often frustrating. As Judy's story shows, not only is breast size, but the shape and symmetry of breasts is of great importance. For Judy, the way she was seen and treated by others led to a very distressing adolescence. Although they framed the issue of symmetry and aesthetic appeal in terms of self-image rather than social perception, these themes resonated with many women as they described their rationale for pursuing bilateral mastectomy.

Fran, for example, expressed a desire to have a physical form that she found personally appealing after treatment. Similar to many women in this study, Fran's assessment of the aesthetics of her breasts before breast cancer impacted her decision to have a bilateral mastectomy.

> One of [my breasts] I liked and one of them I didn't like. (laughs) The one I didn't like had an inverted nipple and was kind of weird and the one I did like is the one that had the diagnosis… it seemed ridiculous to me to just have one off and not the other. Especially since the other one I didn't like anyway. … Now that [breast cancer] screwed up my good boob and I have this bad boob left, so it was like, just get rid of it all.

Fran had a very clear sense of personal aesthetic value for her breasts. For her, a bilateral mastectomy was more aesthetically pleasing to her than the alternatives of lumpectomy or unilateral mastectomy. Similarly, Maggie found the idea of having one breast unacceptable. "I can't deal with asymmetry. I couldn't really picture myself having one big boob and one flat side. That was not reconcilable in my mind whatsoever." The ability to look at one's body after breast cancer treatment and see an image that was identifiable as herself and aesthetically pleasing, was deeply important for many women. The personal visual appeal of their bodies and the connection between their body and their sense of self, separate from the perceptions of others were major motivations for women who pursued bilateral mastectomies.

For many women, issues of symmetry were essential in deciding to have a bilateral mastectomy. Describing this feeling, Allison says, "I figured if I had a single mastectomy and didn't have reconstruction, to then just have one breast, you'd either always have to wear a prosthesis or go around being uneven. … I felt that either way [with or without reconstruction], it would be easier to achieve symmetry by having a bilateral mastectomy." Alison's aesthetic concerns combined with her concern about future cancer risk: "I just didn't want to have to deal with it again in the future. I know this is contrary to what the research is telling us, that you know there isn't a greater risk of getting cancer in the other breast, but I'm 32, that's plenty of time for something to sneak up on me." Other women, like Catherine, made their decisions based on the ways in which physical symmetry aligned with aspects of their identities. Catherine stated, "as an artist, I can say without qualm that symmetry is important to me." For artists, athletes, and many other women symmetry was a critical component of their decision to undergo mastectomy and it's a factor that the medical profession is ill equipped to manage. As Linda states, "symmetry is gigantic."

Edie also expressed great concern for the visual results of her surgery in terms of shape rather than symmetry.

> I come from a long line of artisans and artists and architects. I am not an artist myself, but I am very, very visual. How things look is important to me. And not

> from a vanity point of view. … I don't wear makeup; I don't care that I have wrinkles for example. But certain things, especially shapes are important.

Her visual concerns about her post-mastectomy body are strikingly different from the assumptions surgeons make about aesthetics. In her experience,

> [The first surgeon] thought that the reason I wanted a double mastectomy was for reasons of vanity. So that I would get a better reconstruction. … You know when they tell you, "You need a mastectomy," they expect you to get all upset about that, from the feminine vanity point of view. So it's usually presented as… don't worry we can fix you up right away.

The language of symmetry, in contrast to that of vanity, was particularly important to those who chose to live flat, a point to which I will return in the next chapter. Vanity is tied to expectations about femininity and to an aesthetic for others while symmetry is about a personal aesthetic. Vanity also relates to the belief among medical providers that the reason women choose mastectomy is for a better reconstructive outcome (see Gross 2015). Those women who wanted to live flat needed a different language to explain that the visual effect of surgery mattered to them, but not in a way that reinforced norms of feminine beauty.

Several women with BRCA diagnoses did pursue bilateral mastectomy for reasons that Edie characterizes as vain. For women with BRCA diagnoses, a prophylactic mastectomy (often, but not always, conducted with immediate breast reconstruction) produced more desirable aesthetic results than a similar course of action after a presumably inevitable breast cancer diagnosis. Importantly, the women who had reconstruction did not use this better aesthetic outcome to justify having bilateral mastectomy. It was seen as a secondary benefit of having the surgery, particularly by young, BRCA positive women. Megan explained, "you get to keep the nipples this way and for the most part my breasts will eventually look like they always have." While nipple-sparing mastectomies are controversial because of the possibility of developing breast cancer in the nipple tissue, they remain an option for young, BRCA positive women. After a breast cancer diagnosis, nipple-sparing mastectomies are not an option. Megan had a pleasant view of her breasts before her diagnosis and so retaining her nipples meant retaining the physical aesthetic to which she was accustomed.

The disjuncture between patient concerns for aesthetics and surgeon's assumptions about patient vanity that Edie highlighted create conflict when discussing bilateral mastectomies within medical care. The women in this study made a clear distinction between aesthetics and vanity when discussing their mastectomies. The women's negative assessment of vanity is rooted in their understanding that vanity is connected to how one is perceived by others. Colleen made this point clear in discussing her bilateral mastectomy after her second breast cancer diagnosis. Her initial lumpectomy left her dissatisfied with her appearance. She notes that the difference between her breasts "wasn't super noticeable but it was noticeable to me and I always felt this subtle irritation at that difference." Colleen elaborated, stating, "with my clothes on probably no one else noticed… but I noticed and it bothered me." Colleen and Edie both emphasize the fact that their aesthetic concerns are not vanity because they are not worried about how they appear to others, but rather desire bodies that are pleasing to their own eye.

In Kathy Davis' research with women (1995 and 2003) who undergo cosmetic surgery, she argues that these women are not merely "cultural dopes" or "robots" who act in naïve accordance with cultural norms. In other words, women who have cosmetic surgery are not simply trying to reshape their bodies to meet conventional standards of feminine beauty. Instead, they are making decisions that help to bolster their sense of self for themselves, rather than for others. The resistance of women in my study to vanity and their subsequent use of aesthetics to describe the visual aspect of their decisions about mastectomies may be directly related to the fact that the choice to have a mastectomy contradicts cultural norms about feminine beauty.

As Edie's statement above shows, doctors are as susceptible to these beauty norms as anyone else. When she asked for a bilateral mastectomy, they assumed that she was anticipating reconstructive surgery. Many of the women in this study in fact chose bilateral mastectomies with an express desire to live flat. Regardless of a woman's desire to live flat or to have breast reconstruction, symmetry was largely reported to be central to a woman's ability to build a positive body image after surgery.

Discussion

The decision to have a bilateral mastectomy incorporates several factors including a woman's assessment of health risks and her ability to cope with increased cancer surveillance, concern for her children and/or intimate partner, and her personal sense of aesthetics. Medical knowledge, which informs standards of care, does not adequately account for these factors or dismisses them as vague (and potentially irrelevant) quality of life matters. Central decisions about mastectomy are notions of risk and fear; both of which are somewhat discounted in biomedical studies of this surgery. Understanding fear as embedded within cultural systems aids in understanding not only the various fears expressed by women facing BRCA and breast cancer, but also the ways in which certain fears are given higher medical priority.

Medically, morbidity and recurrence are the risks and fears driving treatment decisions. Surgery is only warranted if it is the best treatment for mitigating these risks, thus alleviating the fears of patients. Within the decision-making process, however, fears centered on disruptions to femininity are implicit yet significant factors in choosing mastectomy. Breast cancer activism and treatment both emphasize breast conservation. At the center of the very public discourse around breast cancer is the concept of “saving” breasts. Breasts in American cancer culture are synonymous with femininity, health, and longevity. Not only do we as a society want women to avoid breast cancer and to successfully eradicate it when it can’t be avoided, but cultural scripts implore women to do so while remaining conventionally feminine, attractive, and sexy (according to normative heterosexual standards). Medical responses to women choosing bilateral mastectomy hinge on cultural fears about femininity deranged when the medical risks and benefits are not clear. As such, when medical providers discourage women with breast cancer from pursuing bilateral mastectomies (if desired) they are implicitly reinforcing cultural ideologies about women’s bodies and conflating women’s bodies with norms of femininity. Additionally, these recommendations serve to reinforce and provide medical legitimacy to these cultural ideologies.

Women with BRCA and women with breast cancer represent two alternate versions of the breast cancer experience. When BRCA positive women choose mastectomy, they are acting within recognized medical disease narratives. Although the removal of their breasts may be an affront to deep rooted gender norms about women's bodies, the surgery is framed by medical providers and researchers as a medical necessity rather than a personal choice. Women with breast cancer who choose mastectomy not only reject prevailing medical knowledge, but they also subvert gender norms as they pursue the removal of their breasts. The tension between the assumptions of the medical community regarding breast cancer care and women's desires for their bodies becomes especially stark as women make decisions about reconstruction after mastectomy. As with decisions about mastectomy, aesthetics and bodily integrity are important considerations for women. In the next chapter, the accounts provided by women concerning reconstructive decisions make even more apparent the centrality of gender ideologies to medical interactions.

Chapter 4

Reconstruction and Recovery

After having a bilateral mastectomy, women face a series of decisions about breast reconstruction. These decisions can be divided into two groups: the timing of reconstruction and the type of reconstruction. In some cases, the timing is determined by the medical team of surgeons and oncologists in coordination with other aspects of treatment like radiation and chemotherapy. There are also multiple types of reconstruction to consider. The most basic is to "live flat."[1] That is, after a mastectomy which removes all breast tissue, the incisions are closed up and left to heal. Women can then choose to live flat, wear prosthetics (foam or rubber forms that fit inside specialized bras or clothing with pockets), or alternate between the two. Alternately, women can undergo surgical procedures to construct the form of breasts.

One common method of breast reconstruction involves the placement of tissue expanders (silicone pouches) underneath the pectoral muscle at the time of mastectomy. After a period of general healing, women then return to the plastic surgeon on a regular basis (as often as twice a week) to inflate the expanders via saline injections of two to four ounces. This process helps to stretch the skin in preparation for breast implants. At the end of a predetermined expansion process (generally 4-6 months), the expanders are removed and saline or silicone implants are put in their place. This procedure may be accompanied by nipple reconstruction or the tattooing of a nipple. Another reconstruction method involves transplanting a patient's own tissue to create the form of a breast (reconstruction with autologous tissue) through either a Transverse Rectus Abdominus Myocutaneous (TRAM) flap, a Deep Inferior Epigastric Perforator (DIEP) flap, or

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[1] Women who choose not to have reconstruction often use the term "living flat" as a more positive description of their post-mastectomy choice. The term is popularized on internet discussion boards and social media sites like Facebook and Twitter.

the somewhat less common Superficial Inferior Epigastric Artery (SIEA) flap. In short, muscle, fat, and skin are "donated" from one part of the patient's body and used to reconstruct breasts. Implants can also be added to these procedures. These are all intensive procedures and the overall complication rate ranges from 5.3% to 46.4% depending on various health factors, cancer treatment plan, and the type of reconstruction chosen (See Jagsi et al. 2014; Brooke, Mesa, and Uluer 2012; Sullivan et al. 2008).

The decision-making process for women who chose to live flat differed considerably from that of women who chose breast reconstruction. The women who lived flat tended to reflect deeply on their decision both before and after while the majority of women who chose reconstruction explained that it was part of the process. For many women who made this choice, reconstructing breasts was presented to me as what they took to be a step of the recovery process, unworthy of contemplation at the time of diagnosis. When I asked women how they decided to have breast reconstruction the first response of many was to say that no other alternative had occurred to them. Delving deeper with all of the women I interviewed revealed complex relationships between participants, their bodies, and a sense of accountability to medical professionals and social norms. In this chapter I first explain the various external forces that influence women's reconstruction decisions. I then examine how participants make sense of their bodies after cancer and how they come to understand their bodies as authentic, normal, and beautiful regardless of their treatment experiences.

Medical Pressure

A woman's decisions about breast reconstruction after a bilateral mastectomy show a constant tension between a woman's identity, medical knowledge, and cultural norms. These factors are complicated by the role of time in the decision-making process. Often the pace of medical decisions in light of a cancer diagnosis is quick, allowing little time for reflection. In this section, I focus on the external factors that contextualize women's decisions about reconstruction. Here I argue specifically that cultural ideologies about gendered bodies shape medical research and care. Women's experiences of interactions with medical professionals also suggest that the care they receive in turn reinforces these cultural ideologies. I present time as a complicating factor that fosters the use of normative expectations of gendered bodies as a reasonable basis for medical advice.

Given the principles of evidence-based medicine and patient-centered, the role of the medical team is to provide scientifically sound information and (in the case of elective surgery) to respect the decision of the patient. In other words, decisions about breast reconstruction *should* be based on data driven research, the balance of risks and benefits, and patient's considerations of her own personal desires for her body. However, the "evidence" used to guide medical recommendations about breast reconstruction is deeply embedded within the cultural ideal of women's bodies as breasted, thus marking decisions that fit with normative expectations as medically sound while others become suspect. While some women did want their doctor to tell them what to do when treatment options were ambivalent, the decision about the final physical outcome of breast cancer and BRCA treatment was understood by research participants to be the personal prerogative of the patient. Failure to present the full range of options, including living flat, is understood by study participants to be a fundamental flaw in patient-physician communication which leads to distrust, physical discomfort, and in some cases years of frustration following the completion of treatment.

Women frequently discussed pressure from medical professionals to have reconstruction. Participants largely felt that their physicians promoted breast reconstruction while remaining silent on the possibility of living flat. Linda was particularly adamant on this issue.

> The problem that I face right now is doctors. The number one people who are planting this idea that life is going to be horrible are the professionals. It is the surgeons, their nurses, these Komens, or all these people saying that your life is going to be horrible if you don't have reconstruction and it's not true.[2] … I've literally heard of surgeons saying to them do you want to be mutilated? To say to a patient, "Do you want to be mutilated?" … When you have doctors who have set this up in the patient's mind that they are less than human and – and some like horrible little person if they don't have reconstruction, what happens if they are one of those people? Where does that leave them, you know? I think on our end, first of all, they really don't need to have that kind of angst over this because it is not that big a deal.

Linda evokes particularly strong language in her description of her surgeon's reaction to her desire to live flat. Her sense that doctors made her feel "less than human" is particularly complex. In her desire to live flat she is acting counter to medical advice, thus questioning the authority of doctors to know what is best for a patient. There is also an unspoken tension between a woman's desire for control over her body and a social and medical context that assumes that having two breasts is the appropriate state for a woman's body.

Linda's belief that the medical profession unnecessarily promotes breast reconstruction is borne out by biomedical research and statements by professional organizations. Within the biomedical field, breast reconstruction is viewed as a critical component of positive psychological recovery after mastectomy because it helps cis women cope with a loss of femininity, mood disturbances, as well as interpersonal, sexual, and marital dysfunction that have been reported as consequences of the surgery (Parker 2004). In an article in the journal, *Plastic and Reconstructive Surgery* (one of the top surgical journals and the top in its field) the research team led by Dr. Edwin G. Wilkins (Professor of Plastic Surgery at the University of Michigan)

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[2] The Susan G. Komen Breast Cancer Foundation is one of the leading breast cancer advocacy organizations. This participant uses "Komens" as a catch-all for the many breast cancer organizations that make up the pink ribbon cancer culture of the United States.

found that “Both immediate and delayed breast reconstructions provide substantial psycho-social benefits for mastectomy patients” and argued that “Breast reconstruction may constitute a ‘reverse mastectomy’ offering the most effective means for restoring psychological wellbeing after a mastectomy” (2000). So, mastectomies are psycho-socially disruptive essentially because they disrupt the relationship between gender identity, heterosexuality, and the body. In other words, choosing bilateral mastectomy for any but a very clear medical reason disrupts the gender system upon which social relations and personal identity are based.

The notion that breast reconstruction improves health-related quality of life after mastectomy has extensive documentation in medical literature (see for example, Dean, Chetty, and Forrest 1983; Nahabedian 2015; Parker 2004; Rabinowitz 2013; Stavrou et al. 2009). While most studies of breast reconstruction espouse this belief, the work of Rowland et al. (2000) provides a dissenting view that women who have mastectomies alone and women who have mastectomies with reconstruction do not report significant differences in body image or feelings of attractiveness. The strength of ideologies of gender and sexuality are so great that these types of studies have little impact because they run counter to common sense reactions to mastectomy. How could a woman have a good quality of life without her breasts when breasts are so central to the embodiment of femininity? Removing a woman’s breasts places her outside the gender system. Such a structural position is seemingly antithetical to a high quality of life.

Nevertheless, the link between improved quality of life and breast reconstruction is the predominant stance in the biomedical literature. This belief is deeply embedded within cultural ideologies of gender and which bodies count as women. In his commentary on Dr. Wilkins research, Dr. Bruce Cunningham (Professor of Plastic and Reconstructive Surgery, specializing in cancer) speaks directly to these cultural beliefs. He states, “The study [by Wilkins et al.]

confirms much of what we know and *intuitively feel* about post-mastectomy breast reconstruction" (2000, 1026 emphasis added). The statement "intuitively feel" is a signal that what we're dealing with at the heart of biomedical interest in breast reconstruction are normative expectations about gendered bodies. This is not lost on those who choose breast reconstruction. Emily (BRCA positive) told me, "It really does come down to the fact that society defines a woman as a human who has breasts. And I think it's kind of like subconscious wiring of, well, I am a woman, and a woman must have breasts, so if I don't have breasts, I'm not a woman."

Both patients and physicians connect reconstructive surgery after bilateral mastectomy to woman-hood. This association is part of a broader context in which cosmetic surgery in particular is framed as a distinctly feminine pursuit (Dull and West 1991). Plastic surgery is divided into two areas: cosmetic (i.e. elective, aesthetic improvement) and reconstructive (i.e. the repair or replacement of "physical defects of form or function") (American Board of Plastic Surgery, Inc. 2016). Dull and West distinguish reconstructive surgery as those procedures that "restore or improve physical function and minimize disfigurement" (1991, 54). The emphasis on function and disfigurement, in the context of breast cancer, is important. The function of the breasts cannot be repaired through reconstruction (as I will explain later in this chapter). The form of the breast may also be somewhat compromised. What is chiefly restored through plastic surgery is the function of the breasts as visual markers of female identity in social interactions. Reconstructive surgery provides a body shape more conducive to doing gender as a woman.

Despite the purported benefits of breast reconstruction, many women who have mastectomies do not have breast reconstruction. The percentage of women who do not obtain breast reconstruction ranges from 41.6% at the most conservative estimate (Morrow et al. 2014) to 83.5% (Alderman 2006).[3] Some plastic surgeons believe that these rates are due to lack of patient knowledge. The formation of BRA-Day, an international breast reconstruction advocacy organization, is a direct response by plastic surgeons to improving awareness about reconstruction, a field that has made dramatic improvements in technique. Specifically, these physicians want women to understand that they don't have to live flat after mastectomy and that many desirable options for plastic surgery exist. The organization promotes the idea that "reconstructive breast surgery can have a positive effect on quality of life for women requiring breast reconstruction" and, according to Jewel (musician and BRA-Day spokeswoman) can help "women feel whole again" after breast cancer (Jewel 2012). Let me be clear, no patient *requires* breast reconstruction. There are many very good reasons for which an individual may choose reconstruction. Using language like "required" suggests that breast reconstruction is a medical necessity and that any other choice is incorrect. This signifies the importance of gender accountability to the medical process and the reproduction of the cultural belief that those who identify as women must have breasted bodies.

The assumption that women don't know their reconstructive options is not well supported by data. According to a study led by Dr. Monica Morrow, clinical oncologist and chief of Breast Service at Memorial Sloan Kettering Hospital, only 15% of women report not knowing about reconstructive options at the time of mastectomy (Morrow et al. 2014). Instead, other factors besides a lack of knowledge about options influences the relatively low rates of reconstructive surgery after mastectomy. In their study of breast

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[3] Morrow et al. also note that rates of reconstruction are lower among racial minorities than among whites. The reasons for this remain undertheorized and my sample was not suitable for this purpose. The intersections of race, gender, and sexuality require additional empirical consideration not just to identify patterns of disparity but to understand how the cultural systems built around these markers of difference shape the experience of cancer and medical care more generally.

reconstruction after the passing of the Women's Health and Cancer Rights Act in 1999, Alderman et al. (2006) found that fewer than 20% of women eligible for reconstruction have the procedure done. They explain that this low incidence was due to poor insurance coverage (which the Cancer Rights Act addresses), concerns about additional surgery, and fear of implants. They also indicate that reconstruction was less likely amongst racial and ethnic minorities. This is significant, according to the authors, because breast reconstruction is tied to quality of life benefits. Morrow et al. (2014) found that reconstruction rates ranged from 25%-35% of women diagnosed with breast cancer from 2003-2007. This study supports the findings of Alderman et al. concerning why women do not have reconstruction, although Morrow et al. found that racial and ethnic minority women were less concerned with additional surgery than white women and were less likely to report that reconstruction was not important. The authors state that "the optimal rate of breast reconstruction is uncertain" (Morrow et al. 2014, E5) yet it is clear that the medical community is interested in why women do not have reconstruction. Issues of access should certainly be addressed because women who *want* the surgery should have access to it. The problem for many women lies in the unquestioned connection between breast reconstruction and a good quality of life after breast cancer treatment.

Some medical professionals frame breast reconstruction as an essential part of the breast cancer recovery process for women, yet research on post-mastectomy satisfaction shows that women are relatively satisfied with their outcomes, even when they don’t have reconstruction. In an article published in *JAMA: The Journal of the American Medical Association*, a research team led by Marlene H. Frost (a researcher at the Mayo Clinic) found that high levels of patient satisfaction were associated with several specific factors, including not having breast reconstruction (Frost et al. 2000) Why then is breast reconstruction framed as so essential to a woman's recovery from mastectomy? Certainly there is a financial component: plastic surgeons would lose income if their services were not in demand. This is, however, a relatively basic argument. After mastectomy, and particularly bilateral mastectomies, breast reconstruction serves to bolster the "womanhood" of women and to restore what is culturally symbolic of the dignity of gender. A pamphlet on reconstruction options available to breast cancer patients at MD Anderson Cancer Center at the University of Texas (one of the premier cancer research and treatment facilities in the United States), assures women that while they do not need to have breast reconstruction, "Living a long, cancer-free life is our goal. Keeping your femininity is just as important too" (Crosby n.d.). The dominant narrative of breast cancer suggests that the disease is not only a threat to health, but also a threat to normative femininity and heterosexuality (Casper and Moore 2009, Sulik 2011). As such, "restoring the feminine body (or at least normalizing its appearance) is a sign of victory in the war on breast cancer" and is deemed essential to personal recovery (Sulik 2011, 15). Medical professionals reinforce this narrative by often strongly encouraging women to have breast reconstruction. Although it is a viable medical choice, most women in this study were not given the option to live flat. Women in this study felt that surgeons assumed patients would want reconstruction and presented options accordingly. According to Sam, "not having reconstruction was never discussed. It was just like, you know, not even – no it wasn't even discussed."

Even when women are forthright with their breast surgeon about their desire to live flat the prevailing assumption that women will want reconstruction can impede communication. Edie, for example, felt that her oncologist kept "harassing" her to get reconstruction. Judy's breast surgeon placed similar pressure on her.

> My surgeon kept telling me I'm going to set you up with plastics because I know you don't want reconstruction but I at least want you to go over there and talk to

> her and see what she can offer you. I did it for my surgeon's sake because he's so God darn nice. I said just to placate you; I will go over and talk to [the plastic surgeon].

Women in this study implied that, breast surgeons routinely set up consultations with plastic surgeons or provided information to convince them to have reconstruction even when women express a desire to live flat. Fran's breast surgeon presented her with a video and asked her to watch it before finalizing her decision to live flat.

> I remember the most offensive thing about this tape, when I just completely lost it, was this woman at the end standing there saying, you know, "Oh, I'm so glad I did this because, you know, if I hadn't it would've been so awful." I mean just – it just seemed like an ad. You know, it wasn't like here's a woman saying she hadn't done it and how happy she is that she hadn't done it, here's a woman saying she had done it and these are the reasons and she's happy she had done it. It was all on this side; it was all an ad for the surgeons to get customers as far as I could tell. And – and it was infuriating to me after having made the decision to have this tape that seemed to imply that I had made the wrong decision because all these people were so happy. And I was now going to be unhappy for the rest of my life, right? So I would say that of all the things surrounding this entire breast cancer thing, that was the most emotional and upsetting part of it.

Often women have to continually justify their decisions to medical professionals. Sally described this as "insensitive" and stated that, "to constantly have to explain myself to doctors was really annoying."

Unlike Fran and Sally, Alison was ambivalent about reconstructing her body and had several consultations with plastic surgeons before ultimately deciding to live flat:

> [Meeting with the plastic surgeon] was hilarious. The first meeting I went to wasn't terrible, but it was (pause) funny. He was a youngish, I mean late 30s early 40s, man. … He asked me if I had been considering having a boob job anyway… like even before this. I mean he's a plastic surgeon right, so his life mission is to produce perfect breasts. … During the second meeting, the things he was telling me didn't really correspond with what I had read about the complications that reconstruction surgery can bring about, the length of the process, you know, how many procedures it takes. And something else he said was this is, like, the fun part.

The women I interviewed explained that reconstruction was presented by plastic surgeons as a reward after the trials and tribulations of breast cancer. This language was particularly distressing to Alison who didn't see additional surgery and the potential complications of reconstruction in this way. Alison's surgeon wasn't alone in the "selling" of breast reconstruction to breast cancer patients as a perk of treatment. Katie's doctor used a similar presentation. “She sort of sold it to me as, and I don't mean that loosely, “As you get a mastectomy, you get new breasts, and you get a tummy tuck.” Pretty straightforward. Which, post-children, sounded like a great deal to me.” Reconstruction is thus heralded as the way to recover by treating oneself after the unpleasantness of breast cancer. For Katie, her surgeon's description of benefits reflected her pre-mastectomy concerns about her body image. This description helped solidify her decision to have reconstruction.

When breast surgeons disregard a patient's desire for a flat chest they often leave flaps of skin, commonly called "dog ears," in order to make future reconstruction easier. In some cases, due to individual anatomy and healing, there is little that can be done surgically to prevent dog ears. In other cases, these skin flaps are left intentionally, much to the chagrin of patients. Linda's surgical result caused some discomfort until she underwent a more minor surgical procedure to remove them: "these were sharp points and looking down they look like shirt collars. They had substance to them, like cartilage." Like several women in this study, Suzy wanted to live flat after her mastectomies. She unfortunately thought that the default option after the successful removal of breast tissue was simply to stitch up a flat chest. Suzy's surgeon purposely left tissue after her mastectomy.

> I didn’t have this discussion with my surgeon because I wasn’t planning on having reconstruction. I just figured I would end up with this nice flat scar that later on, once everything was healed up, I could tattoo over. That was my plan. And I never mentioned it to him, because I figured well, I’m not having reconstruction, why should I bring it up? Six weeks after the surgery, I was still very lumpy, and I asked him about that, and he says, “Oh, you know, that’s the

> excess skin, so that you can get an implant later.” And I’m like, “but I don’t want an implant. … .” Apparently this is a rather common problem, where the surgeons just sort of assume that you want to have reconstruction later, whether they’ve talked to you about it or not. [Prior to surgery] I asked [the breast surgeon] tons of questions and reconstruction just never, ever came up because I had no intentions of doing it. So, for me, the fact that this man assumed that I wanted to have this done, and left skin that I didn’t want, has been quite distressing for me. So I guess that’s one of the things — if I had known this ahead of time, I would have been very emphatic about the fact that I want a nice, flat scar, no excess skin; I’m not ever having reconstruction.

Suzy’s experience indicates the lack of clarity and communication surrounding options after mastectomy. The assumption on the part of her physician that she would eventually want implants was offensive to Suzy and left her feeling disempowered in the medical process. This is exactly what the principle of patient-centered care is meant to avoid, yet this tenet is a double-bind. Given that a conversation about Suzy’s wishes hadn’t occurred, Suzy’s surgeon had to make a decision during the procedure. He relied on prevailing medical norms that breast reconstruction is a positive procedure for women and he acted accordingly. Suzy is a cautionary tale of what can go wrong when gender ideologies inadvertently guide medical care.

Catherine's surgeon found her desire to live flat incomprehensible and required her to undergo extensive, and expensive, psychological screenings before she would conduct surgery. "My doctors were kind of floored that I would want to spend the rest of my life without reconstruction, and I felt as though they kept on pushing it throughout my entire chemotherapy experience. … It was a constant questioning of my mental state and my decision-making process.” For Catherine, the insinuation that she was not mentally stable or that her decision was not justifiable was an extreme insult and tarnished her relationship with the entire medical team responsible for her care. Later in our interview, I asked Catherine why she continued having follow up care with these physicians. She struggled to answer and we eventually moved on to other topics. A week or so later, Catherine sent me an email proudly telling me that after reflecting on our conversation she realized that she had a choice about who provided her care and that she did not have to subject herself to physicians who she felt fundamentally disrespected her. In this email she indicated that she had identified a new medical team to provide her follow up care.

The pressure from medical professionals may begin at the moment of diagnosis and continue through follow up after treatment. Kate believed this pressure to be specific to breast cancer.[4]

> Nobody says, “Let’s put in a fake uterus,” when you have hysterectomy. What's the deal? But if everybody acts like that's the thing to do then you kind of just go with it, right, like we're taking this away, let's put something in. And I was like, well let's get it – let's get her done, like kind of a thing. … People feel like it's something they have to do.

The comparison between a fake uterus and reconstructed breasts is a telling commentary on the importance of visible body parts and gender. To be a woman requires two breasts. A uterus may be a component of woman-hood, but it is socially expendable because it is invisible. Jean Elson's study of women who had hysterectomies suggests that the loss of one's uterus and/or ovaries can be problematic for a woman's identity (2004). As a marker for determining femininity and for daily acceptance as a woman, lacking a uterus is seen differently by the medical profession than lacking breasts. In terms of biological impact, medical professionals arguably should be *more* concerned about removing a uterus given the hormonal complications. After a hysterectomy, the medical focus is on replacing these lost hormones through replacement therapy with synthetic hormones. Replacing breasts with synthetic breasts serves no medical purpose, yet this surgery is strongly promoted within prominent medical journals and by written materials produced by leading breast cancer research and treatment facilities. Taken together, then, the medical

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[4] Kate mentioned one other instance when implants are possible. When her husband was diagnosed with testicular cancer, he had the option to have testicular implants. This was quite laughable to both Kate and her husband.

profession thus sees feminine gender as stemming from hormones and breasts. As such, breasts become the marker of social bio-legitimacy for the identity “woman.” Without them, the body and thus a feminine identity are questionable at best and illegitimate. The pressure women with breast cancer can face from surgeons reflects general cultural norms about women's bodies and social pressure to conform to these expectations. Physicians rely on these cultural norms to guide medical advice and research, thus providing “evidence” that bolsters normative expectations about gendered bodies across social life more generally.

Relying on cultural ideologies of gender is, in part, a way of coping with the pressure of time on decision-making. The time between diagnosis and surgical treatment can range from one week to several months. The amount of time a woman has between diagnosis and treatment (surgical, radiation, and/or chemotherapy) can range from one week to several months and is typically determined by her medical providers and their assessment of her diagnosis. Women who have been diagnosed with breast cancer are making several decisions during this time and trying to process a significant amount of information. A week or two is very little time to deal with the emotional and logistical realities of a breast cancer diagnosis. Breast reconstruction can often begin immediately after mastectomy. Surgeons will remove breast tissue and immediately place expanders as long as the patient is not beginning radiation. As a result, breast reconstruction can seem to be a normal part of the mastectomy process. Kate got swept up in this process and didn't give reconstruction much consideration. "There was lots going on. Nobody's really telling me I need to get reconstructed at all, it's just you can get it. So you kind of think, well, if they're taking things away, I should have them replaced." When Kate later developed an infection and was medically unable to continue with reconstruction until after radiation, she had time to research and consider what it really meant to have reconstruction. As a staunch feminist, she found herself surprised that she had reconstruction in the first place. When she had time to focus on her options, including living flat, without the health concerns that her diagnosis originally brought, she decided that living flat was the best choice for her in terms of both her health and her politics.

Samantha took three months after her prophylactic mastectomy to decide whether or not to reconstruct breasts.

> I was offered reconstruction at the time and I said no, I'm not sure I want to do that yet. And so about three months down the road when I went back to my medical oncologist I said I'm done. No more surgeries. I'm fine with this. I don't feel the need to go back and have more surgery. And I'm grateful that you guys gave me that choice because so many women don't have the choice. … And so in 2011 I had the first mastectomy. 2012 I had the second mastectomy. I finished the chemo in December of 2011 and in July or August of 2012 I went in and said okay, I'm strong enough. Let's do this.

Her surgeons were unusual in that they presented living flat as an option. Samantha described her medical providers as a "dream team" who responded well to her "incessant need to know what's going on and to take time to decide what to do about reconstruction. Between her mastectomies, Samantha described herself as "uni-boob," that is she was flat on one side and often wore a prosthetic. Following the prophylactic mastectomy, she briefly wore prosthetics and then tried living flat in public. This was an important time for Samantha as she determined what shape she wanted her body to have for the long-term.

> I did it more because I was trying to see if I really needed to have breasts, you know, to wear clothing and stuff like that. Where was my comfort zone with not having breasts anymore? … [The prosthetics] kept sliding up to my chin. So I was constantly pulling them down. Finally, one day I thought, this is ridiculous. It's not comfortable and I'm just going to try going without [the prosthetics] and see how I handle that emotionally. At first I was self-conscious that other people would have a hard time with it. And then I quickly realized that, in my opinion, people didn't even notice. But it was a gradual process. I hadn't talked to anybody who had decided to stay flat. I'd only talked to women who had decided to have the reconstructive surgery. And I kept thinking okay, that's their journey but is it mine? And I thought, If I find in this process that a part of my self-image is

> connected to having breasts, and it’s too emotionally hard for me, I’ll go back and I’ll have it done. But I need to try this out, too. And I have the option at any point in my future to go in for reconstruction. But right now I’m totally okay with the way things are.

Time was thus crucial for Samantha. She was able to try out living with one breast, living with prosthetics, and living flat. Her medical team was able to give her the resources she needed to make her decision, including access to medical literature and time. When the time to make a decision about reconstruction is short, however gender ideologies provide a short cut for providers and patients in determining what course of action to take.

Edie also indicated the importance of time in influencing decisions about reconstruction. "Had we done the mastectomy right away, they probably would've put in the tissue expanders because I don't think I would've had enough time to really think it through or research pro and con, you see what I mean, because it was presented as this is just the way you do it." Many women knew what their reconstruction choice would be as soon as they realized breast cancer or BRCA was a likely diagnosis. For others, time was crucial because they had not considered what a breast cancer or BRCA diagnosis would mean for their embodied identity.

The time to research can have drastically different impacts on women with breast cancer and women with BRCA mutations. Women with breast cancer typically have a short amount of time to consider options because the imperative to treat the disease before it can metastasize is so strong. Women with a BRCA diagnosis and no breast cancer can wait for years to decide whether or not to have a prophylactic mastectomy and how to reconstruct the body afterwards. Julie, for example, received her BRCA test results 15 months prior to our interview in October and had a prophylactic mastectomy planned for the following summer. For over two years then, Julie contemplated the impacts of mastectomy and reconstruction on her life. She spent much of this time researching the various types of reconstruction options and determined that a version of the TRAM flap procedure was the best choice for her.

> I have done a lot of research on reconstruction. it's terribly imperfect I don't think that I'm going to come out of it looking the way I look now and that's difficult to accept. I've been doing a lot of research about what gets the best cosmetic results and it seems like using your own tissue, it does produce the best cosmetic results.

For Samantha, time to research has proven essential because she has needed to process the emotional consequences of her diagnosis, the treatment options of surveillance versus prophylactic mastectomy, and the various available forms of reconstruction. While Samantha represents an extreme amongst the BRCA positive women I interviewed, the process she was in the midst of at the time of our interview represents that undertaken by many women. Many BRCA women had time before pursuing genetic testing to consider their options in the event of a positive diagnosis because family members had also tested positive. Seeing close relations grapple with the process and taking time to decide whether or not to pursue testing gave BRCA positive women additional time to consider reconstruction before receiving test results.

A woman's age at diagnosis could also contribute to her assessment of time. Young women diagnosed with BRCA reported that while they may face breast cancer at a younger age than the general population, they still have years in which to make a decision about their diagnosis. Women with breast cancer tend to be older and more settled in their sexual relationships. In this particular study, the mean age of women with BRCA mutations was 36 and that of women with breast cancer was 43.5. Both groups of participants were mostly married (9 of the BRCA participants and 17 of the breast cancer participants). A generally younger age might make women more concerned with reconstruction. In the BRCA group, only Kathy (age 54 at diagnosis) chose to live flat, although Liz (age 29 at diagnosis) also chose to live flat after experiencing complications with her reconstruction. Within the breast cancer group, the majority of participants (16 out of 20) chose to live flat and one was seriously considering deconstruction, regardless of age at diagnosis. While age may be a factor, it seems more likely that the distinction is related to the diagnosis that led to the mastectomy.

Identity and Accountability

While medical advice is an influential factor in deciding whether or not to pursue breast reconstruction, cis women must also personally grapple with the same cultural expectations that permeate the medical profession. The women in this study expressed varying degrees of tension between their self-image, their perceptions of how decisions would impact their social support networks, and what it means to embody gender and sexuality. Susan Bordo argues that the meanings, motivations and consequences of what we do with our bodies are full of ambiguity and contradiction: "to act consciously and responsibly means understanding the culture we live in, even if it requires acknowledging that we are not always "in charge" (2009, 27). Yet, neither the women who choose reconstruction nor the women who live flat are mere "cultural dopes" (Davis 1995) who act at the whims of stereotypical ideas of what a female body should be. Kate believed that decisions about reconstruction are about "having your body presented to the world."

For Margaret, the presentation of her post-mastectomy body in social interactions was central to her decision to have breast reconstruction.

> I think about how okay I would be with not having any breasts and just having just a flat chest. And I would probably, you know, I would be okay with that but I feel like it would make other people uncomfortable. If I'm being honest, I feel like I'm kind of sacrificing what I would choose if I was just choosing for me alone. I feel like I am making a choice based on other peoples' comfort level more than I am my own.

Similarly, Karen worried about making "someone else feel uncomfortable" as a result of her decision to live flat. She went on to explain, "I don't want to be the woman that makes people not know how to look at her." This concern was uncomfortable for her and she wondered whether she *should* push the comfort zones of strangers in order to provide greater visibility for women who live flat. At stake in the concern for making others uncomfortable is a sort of accountability crisis resulting from living flat. West and Zimmerman argue that gender is “the act of managing situated conduct in light of normative expectations or attitudes and activities appropriate for one’s sex category” (1987,127). They embed the importance of accountability within this definition; gender accountability is one’s orientation of behaviors and activities to a given sex category with the knowledge that others will assess this behavior in light of normative expectations for that sex category. To this I would add that accountability is also a matter of bodily presentations that can allow others to easily determine one’s gender. Westbrook and Schilt assert that “in face-to-face interactions, determining gender is the response to doing gender” (2014, 33). If gender cannot be readily determined, then people may become uncomfortable. Although Westbrook and Schilt acknowledge that determining gender occurs through a variety of practices, visible characteristics are the initial criteria used in face-to-face interactions (Kessler and McKenna, 1978). West and Zimmerman’s concept of accountability underlies the fact that visible characteristics are not always as unambiguous as we might expect. While transgender and gender non-conforming individuals may experience the tensions inherent in gender accountability on a regular basis; living flat can shift heterosexual cisgender women from a place of taken-for-granted accountability to a place of ambiguity.

Kate described an instance during which she was uncertain about how her body was being read.

> I wore a white T-shirt one day [to the gym]. I mean, you could really see my form. I don’t have breasts, so it’s not like it’s anything I thought anybody would be paying attention to. … I’m on the stair stepper, and I look out and this kid is videotaping. I was like, I don’t know why this kid is videotaping me. Like, is it

> just funny because I'm a middle aged lady exercising? Is it funny because I look completely bizarre to him?

Kate never confirmed the rationale behind the videotaping incident. Her suspicion that her body was the catalyst for the teenager's interest is a testament to the ways in which visible gender accountability matters not only in social interactions but simply in social spaces. This was a situation in which she was not involved in an interaction with the teenager. He was simply a passerby who caught sight of Kate. By entering a social space individuals are subject to gender assessment. For women who live flat this can create situations that they don't know how to navigate because they expect and want to be viewed socially as women. Living flat can make this more difficult and can result in "interactional breakdown" (Schilt 2010; West and Zimmerman 1987).

Yet, some women found that their concerns about social visibility were unfounded. Linda initially wore prosthetics in order to spare the sensibilities of those around her. This was often uncomfortable for her and she'd eventually take the prosthetics off mid-day.

> Many days even when I was wearing them I'd get halfway through the day and I couldn't stand it one second more and I would run to the ladies' room and rip them off. So I came to work wearing breasts and I'd go home flat. … Nobody died. Nobody fainted. Nobody died. Nobody had a heart attack. They all survived, it's okay.

Not only is the decision about the perceptions of others, but also how decisions about the body impact a woman's identity. Emily was quite clear about this relationship.

> I mean it sounds simplistic but I think that it really is – it really does come down to the fact that society defines a woman as a human who has breasts. And I think it's kind of like subconscious wiring of, well, I am a woman, and a woman must have breasts, so if I don't have breasts, I'm not a woman. So I think it would've felt like I was giving up that aspect of my identity if I didn't have reconstruction.

Breasts are construed as critical visible markers of femininity in social interactions. For Emily, losing this social marker would constitute the loss of her identity. In contrast, several women who chose to live flat stated that they were able to separate their personal sense of femininity from broader normative ideals. Karen explained, "I want to be a woman who doesn't need breasts to still feel sexy or desirable or to feel feminine." After a great deal of reflection, she decided that she could, in fact, be the woman she wanted to be and chose to live flat. Samantha was quite clear on the fact that even though society expects women to have breasts that alternatives exist. "I'm still a woman. I still can feel like a woman. In fact, I feel more feminine than I've ever felt, and it comes from inside, not outside." For those women who find that they still feel or feel more feminine there is a process of acknowledging the social pressure to have breasts and then a releasing of oneself from that pressure. When asked if she faced any resistance to her choice to live flat, Maggie said,

> Most of the resistance I got was from other breast cancer patients. Like, why did you decide to do it that way? How can you do that? How can you do that? How can you like your body that way? Like, seriously? And then, also, the other side to that is a lot of women are jealous. They're like God; I wish I could be comfortable without boobs. And I'm like well, that's interesting. Why don't you just be comfortable without boobs?

For many women the social pressure to have breasts is too great to consider any alternative. Participants report that this pressure is manifest through interactions with doctors, through constant images in the media, from family, and from acquaintances. Seeing oneself as somewhat at odds with this mainstream culture was significant in allowing women freedom to choose to live flat. Catherine articulated this point in terms of a feminist consciousness. "It's feminist for me. It's the right decision for me, but that's not to say that you cannot also make the feminist decision to reconstruct your body. But it's the questioning, I think, that would apply to the word feminist, the ability to question." For her, a feminist consciousness or any perspective that promotes a questioning of the status quo is what can release some women from the physical expectations of femininity. A feminist perspective is not necessarily predictive of a woman's choices regarding mastectomy, but it is the ability to question taken-for-granted assumptions about feminine bodies that allows some women to live flat. The decisions women make about reconstruction occur within a cultural context where, in every social interaction, individuals are expected to remain accountable to gender norms so that others may determine their gender with ease. Additionally, cultural expectations presume that women will have two breasts and that these breasts are necessary to support a feminine identity. Choosing breast reconstruction allows women to remain accountable to these expectations while living flat challenges the norm. Importantly, living flat did not always create interactional breakdown in the average social interaction, nor did it prevent women from cultivating a feminine identity. Regardless of their choice, women often assessed the social impact of their decisions against cultural expectations of what women's bodies should be. This assessment was particularly pointed when considering the impact of their decisions on intimate sexual relationships.

Intimate Partner Concerns

In many cases participants' concerns about how their bodies will be perceived center around not only how their gender will be perceived but also about their identity as heterosexual women. Because gender identity, physical characteristics, and sexuality are interrelated (see Schilt and Westbrook 2009; Schwartz 2007), some women find their heterosexuality suddenly questionable. Whether women reconstruct breasts or live flat, the sexual pleasure that many once associated with their breasts disappears. Following a mastectomy, the breast region loses sensation. Additionally, the reality of losing one's breasts causes some women, like Julie, to disconnect from their breasts.

> Breasts are a huge part of my self-confidence in terms of the way I look. They're a huge part of my sexuality. They've been a focal point of the way I have presented myself sexually to the world. [pause] I don't really consider myself to be very sexual any more. I consider myself to be pretty asexual at this point. I don't want

> them touched. I don't want them looked at. I don't want to think about them. I don't know how its gonna turn out and I'm quite worried about it and I wonder if I'm ever going to feel sexy ever again. [pause] Part of me feels resigned to the idea that I would ever be sexually attractive [crying] ever again, or that I would never be. It's just something I have to accept. I'm quite worried because it's like I don't know how freaked out men are gonna be to be with a woman who has reconstructed breasts. I have a partner of 17 years and he never mentions any sort of disgust at the idea, but at the same time I don't know what he's thinking and it worries me.

Like the trans men in Chapter One, Julie dissociates from her breasts as they become distressing in this situation given her gender identity. Here, Julie's breasts are conflated not only with her identity as a woman but as a sexy, heterosexual woman. For women, sexual attractiveness to men is a defining component of both the gender category "woman" and heterosexuality (Schwartz 2007). For Julie, reconstruction is not an obvious solution to the problem as she is not certain that reconstructed breasts will promote a return to (hetero)sexual attractiveness. Although reconstruction often involves some of the same techniques as breast implants for women without breast cancer, the visual results may be different. Most notable is the lack of a nipple on the reconstructed breasts of BRCA-positive women or those who have had breast cancer. Not only are breasts implicated in a woman's sense of heterosexuality but there is a particular breast aesthetic that is acceptable. Without nipples, reconstructed breasts do not live up to the ideal.

Julie was in a long term relationship at the time of our interview. Other BRCA-positive women who were single, such as Michelle, were especially concerned about how breast reconstruction would impact sexual relations.

> I'm so young, and the guys that I'm dating are young and this is not a normal thing, so I didn't know how a guy that I was dating for the first time would react or if it would be – if it would freak somebody out. I don't think that reconstructed breasts are terribly common at any age, especially at such a young age.

Although she expressed serious reservations about the reactions of intimate partners to reconstructed breasts as opposed to natural breasts, the alternative of living flat was unfathomable. Dating after reconstruction was conceivable to her, while dating while flat was not.

None of the heterosexual women in this study told me that their male partners wanted them to undergo reconstruction. These women all expressed that their male partners' chief concern was with their wellbeing and that the decision was ultimately their own. The concerns of the women I interviewed were sometimes couched in language about their husbands’ expectations. Yet underlying their comments is the connection between heterosexuality, heteronormativity, and gender. In line with Sally's observation about straight women in her social network, women in this study who chose reconstruction did explain that they were personally concerned about the reactions of their partner and what he might not be saying. Amy, who was dating her husband when she was diagnosed with breast cancer, was certain that her husband "would never insist that I have reconstruction and I know that he loves me." Despite this certainty, she also stated, "I don't feel ready to do that [not have reconstruction] to him. … I think it'd be hard on him. Sexually, I think it would be hard on him." Sociologist Pepper Schwartz argued that heterosexuality requires that individuals “are supposed to have certain kinds of bodies that reveal our heterosexuality” (2007,84). Breast cancer and the decision to live flat have bodily implications that disrupt this supposition of a heteronormative social system.

In the previous chapter, I discussed Catherine's decision to spend as much time naked as possible so that both she and her husband could come to see her flat-chested body as beautiful and (hetero)sexy. By reimagining her body as sexy (i.e. desirable to her husband), Catherine was able to reinforce her femininity by virtue of its visibility.

> I almost feel even sort of freer without breasts and even more feminine, whatever that means. For me it almost feels like my body is even more feminine than I have ever been able to experience with breasts. … I love being a woman. I love being female. I have always wanted to be flat-chested. Prior to meeting my husband, I

> dated women. … I think that the gay, lesbian, bisexual community are just more open and willing to accept difference. Perhaps my ease in making this decision [to live flat], my comfort in making this decision, was influenced by my experience in relationships with women.

Catherine's past sexual history with women allowed her see beyond the taken-for-grantedness of heterosexuality and to prevent her flat chest from disrupting her sexual relationship with her husband. Additionally, her practice of nakedness contradicted the sense of desexualization that Ellen felt. Schwartz links being desexed to being invisible while Schilt and Westbrook note the role of visibility in de/legitimating the identity claims of trans people (Schilt and Westbrook 2009; Schwarz 2007). The connection of visibility to sexuality relies on the relationship between the physical body and gender identity. Bodies, gender, sexuality, and visibility are intricately linked in the relationships discussed here. Those women who have a bisexual, lesbian, or queer history reported that the physical changes to breasts and the reality of living flat were easier to manage in comparison to the stories provided by straight women.

Sally, who is married to a woman, was particularly interested in the role that sexual identity plays in making decisions about reconstruction. She told me that many women in her social network "talk about being a disappointment to their husband." She wondered if being a lesbian made it somehow easier to live flat. Sally's question suggests that there is a deep connection between doing gender and doing heterosexuality. As such, those women who do not have to do heterosexuality in their intimate relationships may have greater flexibility in how they do gender, thus making the decision to live flat less problematic.

Maggie, who is married to a woman, also identified as gender non-conforming. This identity generally made living flat easier for her.

> Nobody could really tell my gender right off the bat until I opened my mouth. And so that I didn't mind at all. It was actually kind of nice to not have this assumption of, you know, a woman moving through the world.

Maggie’s gender identity did not automatically improve the sexual implications of her surgery and decision to live flat. Even though her breasts were not significant to her gender identity, the responsiveness of her nipples was important for her sexual identity. Maggie was unequivocal about her sexual attachment to her nipples. "My nipples were fabulous from a sexual perspective." Maggie’s comments help to illustrate a critical contrast between heterosexual women and queer women. Ellen, Julie, and Michelle (all straight) embedded their sexual identity concerns in language about how their actual and potential male partners would react to their bodies. Maggie, although mentioning her female partner, was introspective and focused on her own feelings of being damaged given that she lost a physical sensation important to her sexual identity. Although sexuality is always relational, female heterosexuality is defined in terms of the male gaze and her ability to be seen as desirable. The consequences of this visibility heterosexuality are socially drastic because “if [a woman] is not desired, she does not exist” (Schwartz 2007, 89). Women who are not bound by the norms of heterosexuality and binary gender are able to imagine new ways to remain visible and to bolster their gender and sexual identities.

While both straight and queer women expressed reservations about how their partners would react to their bodies, these concerns were enough to cause some straight women to have reconstruction. No matter what choice women make, the sexual function and appearance of the breasts is compromised. Some women who choose reconstruction do so not because they necessarily want the form of breasts, but they don't want to put their partners through any more difficulty. In other words, having reconstructed breasts is a way to keep intimate relations as normal as possible. These assertions are embedded in a structure of heteronormativity. The women who live flat accept that this supposed normalcy is never going to be achieved and work through it slowly with their partners. Kate likens living flat to the changes wrought on a body after child bearing,

> I feel like I lucked out in feeling like a healthy, sexual, active human being whether or not I have breasts. [My relationship with my husband] is not really based on just the physical and breasts. … I mean if we're in an essentially happy relationship and you have a baby and stretch marks occur, stretch marks are not going to be that big a deal on the other side of it. But if you're already in a relationship that's not so great anyway, then the stretch marks suddenly become somebody's focus.

Intimate partner concerns reflect both the normative gender expectation that women have breasts and the normative expectations of heterosexuality that partners with “opposite bodies” will be attracted to one another. While lacking breasts in everyday interactions may go unnoticed, modifications to the breast become apparent in intimate encounters and disrupt both gender and sexuality norms. Regardless of the reconstructive choice women made, most considered the impact of their decision on their partners, specifically the sexual consequences. Reconstructive decisions were also deeply personal and rooted in how a woman understood the form and function of her body outside of sexual relationships.

Thinking Reconstruction: Personal Factors

In addition to perceived pressure from and concerns about others, women utilized the language of integrity and authenticity in explaining their decisions about reconstruction. Largely, women described their concerns about body function, returning to normality, and aesthetics as significant personal factors contributing to their decision to live flat or breasted. Regardless of their reconstructive choices and the range of factors that influenced this choice, a sense of bodily integrity and authenticity were the backdrop against which all other factors were considered. The term "integrity" commonly refers to the quality of being honest and to a state of wholeness. Shildrick (2010) opens up this definition to argue that bodily integrity is fluid, plastic, and full of possibility. She argues that this state of being complete or whole can even include the incorporation of "alien matter" into the human body. Authenticity is closely connected to the concept of integrity. Where integrity refers to the physical state of the body and one's understanding of that body as whole, authenticity refers to a woman's sense that her body is genuine and true to her own character. Shildrick's expansion of what counts as integrity, and the generally broad definition of authenticity, allow both women who live flat and women who choose breast reconstruction to draw on these themes as they construct their personal narratives of breast cancer in light of cultural expectations about female bodies.

Authenticity

The most basic of these cultural expectations is the normality of a breasted body. A body with reconstructed breasts was seen by those who chose this option as nice, natural, or normal. That is to say, breasted bodies are authentically female. According to Colleen, a breasted body was symbolic of coming through BRCA or breast cancer "unscathed or sort of whole." Sam also equated "normal" with "whole." Her decision to have breast reconstruction was based in a desire to "feel normal again in some way, more whole physically." The repetition of terms like whole and normal belie the importance of the physical body to a sense of self. This is the crux of what I mean by authenticity. Both flat and breasted women wanted to feel whole and normal after surgery. Having breasts after bilateral mastectomy was construed by participants who chose reconstruction as a return to an authentic (that is, “normal” female) body. Those who chose to live flat alternatively explained that reconstruction, due to the addition of synthetic materials to the body or the removal of tissue from other parts of the body to construct breasts, as incompatible with their sense of authenticity.

Madison felt that breast reconstruction made it possible for her to recognize her body after bilateral mastectomy for BRCA: “I did always really like my body. I didn't want to be in a situation where I felt completely uncomfortable in my own body and didn't look a way that was recognizable to me.” Although Madison had “no interest in cosmetic surgery,” her perspective shifted after receiving her test results. The surgery helped her body seem authentic to her in a way that a flat body would not. Cosmetic surgery is at the crux of many feminist debates about gender and the body (see Davis 1997, 2003, and 2009; Dull and West 1991; Heyes and Jones 2009; Morgan 1991; Negrin 2002). Such debates, “evinced a certain flexibility and curiosity about what cosmetic surgery might mean to individuals, and how that meaning might be understood as informing and being informed by a larger social context” (Heyes and Jones 2009,7). Choices about cosmetic surgery, including breast reconstruction, occur through a balance of a woman’s sense of self and her relationship to gender expectations about women’s bodies.

Gender expectations were typically expressed by women through the language of normalcy. Looking normal or “good” meant both recognizing oneself after bilateral mastectomy and being recognizable as a feminine person. As Margaret explains below, feeling normal is also connected to her self-perception.

> I just wanted to get back on my feet and as close to normal, based on how I looked and felt. I mean, they don't look the same [as before] but I guess I feel more comfortable in my own skin. … It represented some kind of normalcy to have something rebuilt there.

Rachel also stated that, "you can never replace what you had naturally," but she chose reconstruction because "it made me feel like I was still a whole person." Underlying the concept of feeling whole is the reaction to disease. Wholeness signifies moving past the diseased state and returning to health. Margaret, who chose implants, told me, "I don't know if I'm ready to look at myself with that much of a reminder, you know with nothing there at all." Colleen expressed similar sentiments. "[Living flat] would be a really harsh daily reminder that this traumatic event had happened." For these women and many who chose to reconstruct breasts, seeing something on their chest besides a scar was about returning to a normal appearance after mastectomy. These women do not want to see "battle scars," as some describe the marks of mastectomy. Instead, they wanted to return their breasts to an idealized state and to diminish their fears of the breast as a trigger of cancerous memory and future anxiety. These concerns never fully leave, but they may become less apparent for some women when there is not an obvious visual marker.

Women who live breasted are supported in this process by constant improvements in surgical technique. These advancements were particularly significant for those women who had seen family members go through breast reconstruction following bilateral mastectomy. Emily had watched her mother go through breast cancer treatment prior to her own BRCA diagnosis. When her mother had a mastectomy, the cosmetic options were far less advanced.

> Whereas [my mother] had a scar straight across her chest, the surgical option that I had, you really can't even tell. Once the scars heal you can't tell that you ever even had a surgery.[5] So that was a game changer for me, that cosmetically I would still be pretty much normal.

For Emily, a highly visible scar was a symbol of illness and a non-normal body. Scars mar the visual integrity of the body and for many women create an unappealing aesthetic. Appearing not normal may reinforce the feelings of cancer anxiety that led to a bilateral mastectomy initially. Reducing the visibility of scars through improved surgical methods is critical for women like Colleen.

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[5] This is only the case if a woman chooses reconstruction. Although surgical techniques have improved, any surgery includes the possibility of a scar. If a woman has reconstruction, the resulting breasts will overhang any scarring (however minimal) left from the mastectomy thus making the scar extremely difficult to see.

> I think the technology piece did play a role… I did spend some time, reading about the technology, asking a lot of questions about the aesthetic piece because that was important to me. It definitely made the decision easier when the plastic surgeon said, your body's really going to look the same, you're going to just have small scars kind of under your arms. … It's not going to be a huge scar across your chest. Once she said that, it sort of clicked for me.

For Colleen, it was both the visibility of scars and her concern that reconstructed breasts would look significantly different than her biological breasts that caused aesthetic angst. Aesthetics thus incorporate multiple concerns for those who reconstruct breasts, such as whether or not the reconstructed breasts will look normal. Madison was particularly emphatic in her agreement with this point. "I was like, 'Oh my God, I'm going to be disfigured. And I'm not going to look like a normal woman and I'm going to you know look like a weird crazy person under my clothes and everything's going to suck forever." Breast reconstruction was Madison's insurance against appearing like a "weird crazy person" when naked. To not have normative breasts under one's clothes is here considered antithetical to being a normal woman.

Women who live breasted also described their fears about recognizing themselves after surgery as well as having others view their bodies positively according to the idealized female body. This was a determining factor in Michelle's decision to have reconstruction after a prophylactic bilateral mastectomy.

> I'm [young] and I am single and I'm going to have these boobs the rest of my life. I need someone who's going to do a damn good job at making me look as good as I possibly can. … A lot [of my decision] was what I'm going to have to look at in the mirror every single day. … I wanted to look good in clothes, of course, but also I wanted to not be totally freaked out looking at myself in the mirror.

The naked aesthetic is not only significant in terms of reminding women of the trauma of surgery, but also reflects the internalization of normative expectations about what a female body should look like. Choosing breast reconstruction in many ways indicated a degree of personal affinity and attachment to this norm.

Michelle's statement above also indicates that it is not just the appearance of the naked body that matters for women. Jody acknowledged that her reconstructed breasts would look different from her biological breasts. For her, it was the clothed appearance that was of the greatest concern. "I just wanted to have something there. That's pretty much it. If not for my piece of mind, but for the ability to at least fit in some clothes. … I don't know if I'd like to have nothing there, because I kind of have a belly. I need to have something there. At least for me. … I never intended my reconstruction to go very far, just to have basic mounds." The phrasing of "basic mounds" suggests that Jody's concern is not with the naked form. Instead the importance of these mounds is to improve the fit and appearance of clothes and to mask her belly which she felt would be unpleasantly prominent without breasts. Rachel also emphasized the importance of clothed appearance over naked appearance.

> I always felt that if I could just look decent in clothing and not have to wear a prosthesis that was going to be just fine for me… [as long as] nobody would know the difference [when I was clothed]. That was really all that I was concerned with.

For Rachel, clothed appearance was important in deciding how to reconstruct her post-mastectomy body. Prosthetics would have provided the shape she desired, but would have limited the variety of clothing she could wear. Given the importance of a clothed appearance, Rachel could not consider prosthetics. These comments suggest that women who chose to reconstruct their breasts wanted to retain the typical feminine form while clothed and to have some semblance of the naked appearance to which they were accustomed.

Feeling whole also meant, for some women, making choices that honored the importance of breasts in their life before cancer. Rather than focus on the visual impact of having a breasted body, Nicole emphasized the affective importance of her breasts.

> It's not because I'm worried about how I'm gonna look afterwards or anything like that. It was solely because [my breasts] *mean* something to me and it's because I've breastfed my children and I loved breastfeeding them. … It was, wow, the breasts that fed my children are no longer gonna be there when I have this surgery and that that's what gets me. … I found out they've started doing surgery a little differently so they'll still kinda look the same. I'll feel like they're mine. [And] hopefully I can have the nipple sparing surgery, so at least I'll still have a part of me, the breasts that fed my children.

As a BRCA positive woman, Nicole had the option of a nipple sparing mastectomy. This is largely unavailable to women with breast cancer. Nicole believed that retaining her nipples would help her stay connected to her experience of breastfeeding which was integral to her self-image. Femininity in Nicole's statement is not simply a matter of aesthetics, but also incorporates the experience of motherhood. Adding silicone implants does not threaten her bodily integrity because the fact that she retained her nipples allowed her to integrate the foreign material into her sense of bodily authenticity. Further, nipple retention means that for Nicole a critical component of her embodied history as a mother remains physically present.

The ability to incorporate foreign material into one's self-perception was distinct to the women who chose breast reconstruction. Madison felt like her tissue expanders "totally feel a part of" her even though "they're really hard and they don't feel natural." Madison expresses in this comment a sense of authenticity (that the synthetic material of the expanders are part of her) while at the same time acknowledging that her bodily integrity is compromised because the implants feel unnatural. Michelle was quite candid about the unnaturalness of tissue expanders. Instead of painful, she described them as fun.

> It was kind of hilarious to like just be laying there and watch [the expanders] pump up and see you breasts get bigger right in front of your eyes. … It kind of became an exciting process just because with each step you're a little bit closer to being done.

While Michelle specifically meant being done with the reconstruction process, her statement also indicates an endpoint in identity work where her physical form will allow her to be back to her old self. Additionally, this process of re-identifying with one's body is a response to cancer's recidivism. It is a form of affective protection against the possibility of a recurrence. To have breast reconstruction after a prophylactic bilateral mastectomy is a return to normal feminine embodiment which belies the body's history of cancer.

Integrity

In contrast to the authenticity drive that resulted in breast reconstruction, a rhetoric of integrity was often crucial to women choosing to live flat. Integrity encompasses both sense of a body that is free of technological intervention and that has full muscle function. Linda, for example, held the view that reconstruction utilized "foreign bodies… [or] cannibaliz[ed] good parts to make things that kind of look like breasts." Both reconstructive options, expander and implants or the TRAM flap procedure, compromise a woman's bodily integrity by adding foreign material to the body or taking away from other parts of the body.

For many who live flat, sacrificing function for appearance was unacceptable. Karen was one of several women who were uncompromising in their desire to retain their normal muscle function.

> The whole process of putting something behind your pec muscle and slowly expanding it, painfully, to stick some other foreign object in your body or maybe take some other part of your body and put it in there, it all feels really strange. Especially because you don't get back sexual function or breastfeeding ability. So all of that is so that you can make other people comfortable with how you look. And I know that's not how it is for everyone, like for other people they need to be comfortable with how they look, too. But it turned out I am comfortable with how I look. It's other peoples' issue sometimes.

Karen's statement makes clear that there are two central factors, in her opinion, that figure into decisions about reconstruction: a woman's comfort with her body image and the function of the body. How a person feels about his or her body after reconstruction may include a consideration for how they are viewed by others, but for Karen this concern is less relevant than her physical capabilities following mastectomy.

> Sandy was especially concerned about her muscle function after bilateral mastectomy. I like my muscles the way they are. I am a competitive athlete. I am scrawny enough that the only reconstruction they could have done would've been the expanders, and do not mess with my pecs, thank you very much! Alternatively, if I had the body fat, I wouldn't have wanted my core disturbed for a TRAM. I would not have wanted someone to play with my lats. Breasts are so much less important to me than having the integrity of my muscles.

The importance of muscle function arises as a concern for many women following breast reconstruction. Following mastectomy individuals experience a loss of sensation in their chest and inability to breastfeed. Breast reconstruction also severely limits muscle function. TRAM flap procedures impede the function of the chest muscles, the use of the transplanted muscle tissue, and the remaining muscles at the donor site. The use of expanders and implants also limits the function of pectoral muscles, though not as severely as transplants. Like the women who live flat, Jody (who lives breasted) was wary of the TRAM flap procedure because she "didn't want to lose access to those muscles." However, she expressed some sadness that she was not fully informed about the loss of functionality from expanders, "I wish I had known that I was not going to have as much use of my pectoral muscles. It's more of an inconvenience than it is an actual hindrance." Several women described this inconvenience in terms of their inability to open jars or to slice hard objects such as carrots.[6] Yet, this physical hindrance did not lead Jody to regret reconstruction. For many women who live flat, the idea of compromising muscle function is simply unthinkable.

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[6] Medical literature suggests that although these types of physical consequences do arise from breast reconstruction, the effects are typically short term. Such impacts are expected to improve with a carefully managed physical therapy, however this is not consistently included in the plan of care (Smith 2014). It stands to reason that this common lack of physical therapy could explain the experiences of women in this study.

Along with a concern for physical functioning, women who live flat explained that having foreign materials or rearranging tissue is appalling and not worth the end result of conforming to normative standards of female bodies. Edie had a fierce reaction when her doctors offered up options for breast reconstruction.

> I remember thinking not on my fucking life! I mean the idea of having foreign material under my skin is a hideous thought to me. And then when I realized that for the surgery they actually disconnect your pectoral muscle to stick the silicon under the muscle I was like, are they fucking kidding me? I mean, not only does it hurt like hell, but [women who do this] have diminished function.

The combination of pain, the fear of losing muscle function, and Edie's visceral reaction to foreign material rendered breast reconstruction impossible for her. Sandy also felt that breast reconstruction was "too insulting to the body" given the added risk of infection and pain associated with reconstruction in addition to the possible risks of mastectomy.

The insult to the body is, specifically, an affront to the body's integrity. This is sentiment is evident in the frequency with which women who live flat expressed that their bodies had been put through enough. Kate, who initially had implants, "deconstructed" her breasts after a string of complications and explained the common feeling among flat women that the body was threatened by medical procedures.

> You kind of feel like you want to own something and you need some agency, right? So it's like, alright, I'm losing the breast, I'll get back the breast. I'll do reconstruction. Like, people tell you, you know, you do chemo, you lose your hair but it comes back. You're not prepared that you're metamorphosing, right? You're kind of thinking you've got to get back to where you were. You're hanging on to life here and you think that life as you have known it before is better than the scary life that's being proposed. [After the complications with reconstruction] I was just like, enough. Enough. Stay away from my breasts. Or lack of breasts. Stay away from my body. I don't want anything invading – it was awful.

In the passage above, Kate posits reconstruction as a return to the physical state before mastectomy. Like re-growing hair after chemo, Kate believed that health care providers present breast reconstruction after mastectomy as a procedure that will allow a woman's body to return to normal. Once the reality of reconstruction set in (the unnaturalness of the "mounds" and the health risks of complications), Kate had to rethink bodily integrity. She became adamant about reconstruction as threatening, feeling strongly that physicians needed to stay away from her breasts. At the same time, she was evolving. Her understanding of the connection between her identity and her body shifted to a place where reconstructed breasts were not in line with her sense of self. Further, Kate raised the issue of agency in the passage above. In making decisions about reconstruction, women are confronting not only cultural ideologies but the way those ideologies have been institutionalized through medical practice.

Kate was critical about the reality of reconstruction as a way to meet these ideals.

> You're basically getting mounds put in so that your form looks the same to the outside world. But what's really there when you look naked in the mirror will no longer be anything that resembles the breasts that you've grown up with.

Edie similarly invoked the body she grew up with to make sense of living flat.

> The way I look now is how I looked when I was 11. I mean, I remember looking like this. I remember feeling well while looking like this. I remember being happy while looking like this. To me, it's not that big a deal.

Edie's harkening back to adolescence is important here. That phase of life is a critical phase in the act of becoming an adult. The onset of puberty at this time is a physiological marker of becoming a "real" woman. In his study of transgender men, Henry Rubin asserts that the physical changes (breast growth and menarche) that occur during puberty can be particularly distressing for trans men. These changes mark a transition via "the physical and hegemonic criterion for adult womanhood" (Rubin 2003, 99). Prior to puberty, the bodies of boys and girls are visibly similar in most social interactions. Edie's return to her adolescent understanding of her body is an act of what Underman calls "affective disposition, a particular way of feeling embedded in a cultural context" (2015, 180). In order to make sense of the physical changes wrought by bilateral mastectomy, women who live flat had to rethink their relationship to their cultural context. Prior to puberty, women who live flat generally thought of themselves as female without question. This experience provided a model for reconciling their new, flat body, with their gender identity. Kate and Edie both described the end result of the process by which some women attempted to align their embodied identities with a culture context imbued with normative expectations about women's bodies.

Like the women who live breasted, the act of recognizing one's body and being recognizable to others remained important to women who live flat. In other words, the visual effect of reconstruction played an important role in deciding what physical form the body would take after bilateral mastectomy. Many women who live flat were somewhat critical of being overly concerned with appearance. Sadie, for example, asserted, "Reconstruction is not reconstructing anything. It's putting an unfeeling lump of something on your chest so your clothes look better." Similarly, Catherine felt that choosing breast reconstruction was linked to a desire to comply with societal norms about what a female body should be. For her, the complications of additional surgery were too great a risk simply to regain a normative form.

> I would love to see the shape of breasts on my body, but no, I am unwilling to do what it takes to have that. I mean I did talk to them about different types of reconstruction, and I don't have enough body fat. I don't want to put my body through the multiple surgeries it might take to get it back, and I'm unwilling to move tissue from this place to that in order to, I don't know, conform. And I do feel that it is an issue of conformity.

Living flat opens space for a critical examination of standards of feminine beauty. Several of the women who live flat conflated conforming to social norms as vanity and attempted to distinguish their interest in a personally visually appealing body after mastectomy. Many were careful to explain that they weren't vain: they weren't particularly interested in make-up or fashion. Their examples of vanity were stereotypically feminine behaviors. That is, they established that they had a history of physical non-conformity. Despite this, looking good was important to most of the women who live flat. Karen stated, "I think I look good. [Breast reconstruction] seems like a lot to go through just to look a certain way." Reconstruction is cast as a vain choice, yet living flat remains aesthetically pleasing. Many who chose reconstruction are proud of and pleased with their appearance. Catherine, for example, did research on living flat and found self-portraits by a photographer who had done so. "She had taken some topless pictures of herself on a beach, playing with her children and her results were absolutely beautiful. So I decided at that point to go bilaterally flat."

That women who live flat see their bodies as beautiful creates a stark contrast to how they view reconstructed breasts. Many women turned to the Internet to research images of reconstructed breasts. Women, like Edie were appalled by what they saw.

> The first thing I did was to go look for reconstructed boobs on the internet. … I started looking at these things and I'm like, holy shit, because to my way of thinking this stuff looked horrific. I mean, we cancer ladies, we like to call them 'Frankenboobies.'

Ashley also commented on "the Frankenstein-ness of how they look when they're done." Similar sentiments are expressed in subtler ways. Rather than monstrous, Linda felt that reconstructed breasts simply do not live up to the expectation that they will appear similar to natural breasts. "The thing is, these are not breasts. They do not make breasts. They make things that kind of look like them, but they are not breasts. They are dead lumps." These women clearly express the view that reconstructed breasts are really just lumps of material whether synthetic or transplanted from other parts of the body. As Kate researched reconstruction options after some complications with expanders, she decided that the aesthetic of a breasted body was not desirable. "I'm learning that it's just sticking mounds on my body. And then they tattoo nipples on. I'm like, why do I need that? If I need a tattoo, I'll get one on my ass."

These sentiments are tied to a fairly widespread disdain for vanity and preferential focus on function. As Ellen explained, "What's the point? There's no feeling, they are ugly, you don't get your nipple. So what's the point of having boobs for vanity purposes?" Many who live flat balance aesthetic considerations with issues of functionality. In other words, if reconstructed breasts don't function as do natural breasts and if they are unappealing visually (at least without clothes), then why bother? When I asked Fran why she didn't have reconstruction, she responded simply, "Why have it?" For the participants who live flat, reconstructed breasts mean conformity to cultural norms and fail to live up to their aesthetic concerns. The disdain for vanity and decision to live flat were connected to a strong undercurrent of independence. That is, these women insist that they do not to look for approval from others regarding their decisions about their body nor do they require others to affirm that their bodies are beautiful. Edie explained that in her decision-making process to live flat she didn't consult her husband. She asked his opinion only after she had made up her mind.

> I would never ask him [if he'd like me to have breast reconstruction]. I told him at one point after researching that I had more or less decided that I probably would never get reconstruction. I asked him if it bothered him in any way. And he said, oh for God's sakes! And then he said look, I would prefer you don't have reconstruction. He's shit-scared of anesthesia; he doesn't like me put under. He also doesn't like silicone boobs. He associates it with transvestites (laughs).

Clearly, women such as Edie care about how their intimate partner will react to their decision, but this concern does not extend to a point where if Edie's husband had said it bothered him that she would then have breast reconstruction. This is not specifically about her husband's reaction, but rather Edie's decision begins with her relationship to norms of feminine beauty. Her assessment of her husband's reaction simply reinforces her decision rather than swaying it.

In addition to being centrally about how one is seen by others, vanity is also connected to beauty. For women who choose to live flat, reconstructed breasts cannot be beautiful, but flat chests can. Even though women who live flat embrace a narrative of independence and personal choice, it is rarely this simple in practice. The perceptions of others do matter to both those who live flat and those who reconstruct. It is also important to many women who live flat to effect change in public perceptions of post-mastectomy bodies. Several participants (both women and men) participated in David Jay's photography work, "The Scar Project," as well as other artistic projects to bring alternative images of breast cancer into the public eye.[7]

In Bordo's assessment, all women are under a cultural imperative to be beautiful. Even as women who live flat insist that they make this choice in contradiction of beauty norms, personal aesthetics and the importance of beauty are still strong forces with which women contend.[8] Women who choose breast reconstruction and those who choose to live flat both rely on similar narratives that contrast a narrative of aesthetics with one of vanity. The concepts of beauty and vanity are contested within feminist scholarship (see Bordo 1993 and 2009; Davis 1995, 2003, and 2009; Felski 2006; Furnham and Swami 2007; Gagné and McGaughey 2002; Gimlin 2002, 2007, 2010, 2013; Jain 2013; Stuart and Donaghue 2011). Felski argues that there has been an evolution in feminist understandings of beauty from "the rhetoric of victimization and oppression to an alternative language of empowerment and resistance" (2006, 280). Beauty thus becomes a powerful discursive tool that can be deployed in the construction of self-identity, as is the case for the women in this study. For these women, beauty remains distinct from vanity. Avoiding the

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[7] One of the first images of a woman living flat after breast cancer in the mainstream media was A *New York Times Magazine* (1993) cover story depicting artist Matuschka's mastectomy scar. The cover received an extreme amount of both positive and negative responses, thus opening space for ongoing efforts to bring these types of images to the mainstream.

[8] These are pressures that are increasingly faced by men as well (see Chaline 2015; Luciano 2002).

language of vanity, in favor of aesthetics, is a way for women to set themselves apart from what many find to be the problematic relationship between cultural beauty norms and the culture of breast cancer awareness (King 2006, Sulik 2011). Beauty remains important to both women who reconstruct their breasts and to women who live flat. The distinction, according to those who live flat, lies in whether one is primarily concerned with one's own body image or how that body appears to others.

What became clear through conversations with these women about their experiences is that regardless of how participants use the language of normalcy and naturalness to explain their decisions, women who have breast cancer end up with bodies that are modified. According to Catherine, no matter what choice a woman makes, she is choosing some type of reconstruction.

> I chose a non-conventional reconstruction, and conventional being reconstruction. I didn't get the shape of breasts on my body, but if you think this isn't reconstruction you're kind of crazy. I reconstructed my body. This is a form of reconstruction.

Kathy felt quite similarly: "I've had a woman say recently that she got reconstruction immediately after getting her mastectomy and she said she was so happy she still had a chest. I still have a chest. Just because I didn't get reconstruction doesn't mean I don't still have a chest." Both Kathy's and Catherine's statements reflect the sense that breast cancer alters, at least temporarily, one's sense of integrity; the state of being complete. When women make decisions about reconstruction they primarily act in ways that help them to regain a sense of an integrated body and which reflect their sense of themselves.

Still, these choices often come down to a woman’s understanding of her embodied identity and her relationship to femininity. Samantha, who lives flat, came to this understanding through participation in a public art installation on self-image that involved having her naked torso painted.

> I stood there for four hours while [the artist] painted me and answered people's questions. I was there to show people that regardless of what your body is going through, you can still be whole. … I need to put myself out there and go, okay, I'm still a woman. I still can feel like a woman and in fact feel more feminine than I've ever felt. It comes from inside, not outside.

For Samantha the feeling of wholeness, of authenticity, is not specifically tied to her decision about reconstruction. Rather, it was intrinsically about her self-image and her understanding that this self-image was connected to her own perceptions rather than those of others. Emily, who lives breasted, was also reflexive about this process. She told me, “It would be great to say that I'm strong enough as a person and have this identity completely separate from my physical self but that's not the case." Although Samantha and Emily had different physical outcomes, they describe a similar process where women reconcile their choices about their bodies with a feeling of femininity. Strength here can be understood as a process of becoming. Samantha expressed insecurity about living flat, but her participation in the art installation served as a catalyst for re-thinking what her body meant for her identity as a feminine woman. While mastectomies and reconstruction may be a threat to bodily integrity, how a woman incorporates these changes into her sense of self is a strong indicator of her choices about reconstruction. While flat or breasted are both forms of reconstruction that reflect a woman's sense of bodily authenticity. Reconstruction requires additional emotional work to define bodily integrity as including foreign substances. Both choices require that women grapple with feelings of authenticity and integrity in order to determine what level of intervention they can experience while retaining an identity with which they are comfortable.

No woman in the study remarked that her choice about reconstruction was right for everyone. What they all reiterated was that the method of reconstruction, be it living flat; living with prosthetics; having implants; or using one's own tissue to create breasts, was an individual choice based on how a woman reconciled the changes in her body with her identity.

Discussion

What is clear from participant interviews and a review of the medical stance on bilateral mastectomies is that physicians anticipate conflict with patients when reconstruction would adversely affect treatment outcomes. This stems from an assumption supported by biomedical research that patients want or need breast reconstruction (i.e. the creation of breast forms) in order to recover emotionally and physically from treatments for breast cancer and BRCA. When patients express a desire to live flat, physicians may make an effort to allow for a possible future reconstruction by leaving excess tissue that will make reconstruction easier. Breast surgeons may also try to convince women that they should seriously consider reconstruction by requiring consultations with plastic surgeons or psychologists and by continually asking if patients have changed their minds.

Often the timeline of breast cancer is fast. Women may be diagnosed and have surgery within the same week in some cases. Given the speed at which decisions must be made it can be difficult for surgeons and patients to reconcile their different perspectives on life after treatment. The surgical perspective is one of necessity and expediency, halt the growth of or remove the tumor completely as soon as possible. Patients, on the other hand, grapple with complex concerns about their health, their bodies, and their identities. The ability to make an informed decision is compromised in many cases by the speed of the care cycle, the medical silence on the option to live flat, and a minimization of the risks of reconstruction. No woman in the study remarked that her choice about reconstruction would be right for everyone. What they all reiterated was that the method of reconstruction, be it living flat; living with prosthetics; having implants; or using one's own tissue to create breasts, was an individual choice.

Yet, it is interesting to consider what “choice” means in this context. Bordo cautions that this rhetoric of choice can be misleading.

> In the culture we live in, individuals are caught between two contradictory injunctions. On the one hand an ideology of triumphant individualism and mind-over-matter heroism urges us to 'Just Do It' and tries to convince us that we *can.* ... But on the other hand, while consumerism assures us that we can (and should) 'just do it,' it continually sends the contradictory message that we are defective, lacking, inadequate. (2009, 27).

Regardless of their reconstruction choice, women who choose bilateral mastectomies make these choices in a cultural context that presumes that women have two breasts. Whatever decision women make following bilateral mastectomy, it is a decision that requires anxious bargaining between aesthetic, sexual and health norms while contending with fear of cancer’s recidivism. As Bordo suggested, an ethos of patient empowerment and choice only goes so far given the implicit impact of the gender system on medical care. The tension between social structure and agency is a classic sociological debate and bringing this tradition to bear on breast cancer is useful analytical approach. Eriksen concluded her investigation of breast cancer narratives and hegemonic femininity by stating that it is "tempting to view the response groups described here as simply a product of social structure and culture… However, to describe women only in this way is to present them as foolish and passive, and one of my most important findings is that women showed considerable agency in dealing with breast cancer" (2008, 253-254). Crompvoets similarly structures her study of breast cancer through the investigation of "how the microparticulars of women's accounts [of breast cancer] fit with macrocultural structures" and how "breast reconstruction fits with feminist ideology" (2006, 4). The influence of the gender structure, and femininity in particular, is powerful in the experience of breast cancer. Patients and providers must work within the institutional norms of the medical profession and in the context of the gender structure. At the same time, the very structure of gender is being performed into existence through the experience of breast cancer, a disease that threatens commonsense ideas about femininity and its situatedness in the body.

Evident in narratives about the interactions between post-mastectomy patients and physicians is the importance of ideas about feminine bodies to physical and social well-being. Femininity was important to many women regardless of their reconstructive choice but the narrow association of this trait with particular physical characteristics was shown by research participants to be faulty. Yet, the commonsense association between visible physical traits and gender identity remains deeply influential on medical practice and also for participants. The women who spoke about feeling more feminine while living flat explained this in terms of the visibility of their bodies. Women like Samantha felt liberated to wear more revealing clothing than they did pre-mastectomy. Catherine described wanting to make scars sexy and her desire for clothing that revealed a bit of scar. Although these women want to disassociate femininity from breasts, femininity remains a matter of the visible body. As these women reconsider how to do gender in everyday life, the visibility of their gender remains critical to their identities and social lives.

Conclusion

In 2008, Thomas Beatie gained national attention after publicly announcing his pregnancy. Beatie, a transgender man, was billed by major news media outlets as “the pregnant man.” He was interviewed on The Oprah Winfrey Show and 20/20 and appeared on several magazine lists of “shocking moments” and “oddball news stories” (*People Magazine* 2008*; Time Magazine* 2008*)*. LGBT media proudly added him to lists of trans pioneers (*Huffington Post* 2011). His story received diverse reactions from pride in the LGBT media; to confusion, shock and disdain in more conservative outlets (Baqi 2011; Haaland 2008; Martindale 2012; Raezler 2008). Since Beatie’s coming out as a pregnant man, several other trans men have been profiled in standard media and social media (see Birkner 2016; Huston 2015). Central in the response to these stories, whether positive or disdainful, are questions of whether pregnant men are “really” men. Such criticisms hinge on the notion that biology is the reality of gender—what body parts you have, and more specifically, what you do with them determines the truth of your gender.

As more trans men went public with their stories of pregnancy, 2016 also marked the first uterus transplant in the United States (Kennedy 2016). Four years earlier, Swedish surgeons transplanted uteruses into two women resulting in the births of four babies (Knox 2012). Although the procedure has been controversial and the one conducted in the United States failed immediately, it has generally been reported as an impressive medical advancement. Although, as Dr. Michael Green told a reporter at National Public Radio, “Nobody needs a uterus to live,” he considered it “one of the next logical things that people might do” (quoted in Knox 2012 and Kennedy 2016). Unlike stories about pregnant trans men, news stories about uterus transplants tend to focus on the medical and scientific aspects of the procedure and use language such as “hopeful,” optimistic,” and “quality of life” (Grady 2015 and 2016). A story in *The Atlantic* covered the many “high-tech” and “straight from sci-fi” approaches under investigation by bio-medical researchers to aid cisgender women in becoming pregnant including uterus transplantation, regenerative medicine, and bioengineered organs (i.e. growing a uterus from stem cells) (Don 2015). These procedures, experimental and risky as they are, have a media presence that evokes a kind of medical altruism that answers the prayers and desires of women to bear children when they are physiologically unable to do so as a result of various physical conditions.

These differing stories of pregnancy are examples of bodies doing what they “should” and “shouldn’t” do based not on biology but on ideas about what it means to be a man or a woman and society’s inability to separate the biological or physical capacities and traits from a person and their gender. The gender system relies on a taken for granted link between gender identity, bodies, and ideas about what it means to be a man or a woman. In the case of pregnancy, to be a man is irreconcilable with being pregnant and to be a woman is intrinsically tied to the desire to bear children. These normative standards are troubled by transgender men and women without uteruses or with uteruses that do not function as expected. If a man becomes pregnant, he cannot truly be a man. That is, by acknowledging, using, and even celebrating his ability to bear children, he opens for scrutiny his identity claims. A woman who becomes pregnant, no matter how, solidifies her status as a woman. These stories suggest that the medical profession plays a critical role in naturalizing the linkages between bodies, identities, and cultural ideologies, as well as presumed biological differences between women and men. The stories of pregnant transgender men include some medical information, often in support of the spectacle, while those of the uterus transplants portray biomedical information as beacons of progress. In everyday interactions, trans men and women without uteruses can successfully do gender because the visual cues of their bodies support their identity claims. The medical context, particularly medical exams but also the state of pregnancy, are moments when those cues are stripped away. The concept of doing gender, while hugely influential as a theory of social interactions cannot account for instances when the body is fully visible.

Throughout this manuscript I have argued that gender is problematic for medicine, but not in the way that might be readily apparent. Certainly there are health disparities between and amongst men and women. Gender also remains influential in matters from physician-patient trust to the training of medical students and the type of specialties individuals choose (see, for example, Arnold, Martin, and Parker 1988; Risberg et al. 2003). As biomedical research has begun to attend to physiological differences between women and men, clinical practice has shifted to account for these differences in the diagnosis and treatment of disease. Yet gender is more than simply a variable impacting health distribution and professional composition. Instead, I have argued that medical practices are embedded within the gender system and as such are influenced by commonly held beliefs about what it means to be a man or a woman. These beliefs are specifically tied to the physical body, and as such, the authority of medical providers becomes critical in rendering legitimate and recognizable a patient's gender while at the same time reaffirming normative expectations for appropriately gendered bodies.

Social bio-legitimacy combines feminist thinking on embodiment and subjectivity with the socio-political imperatives of biocitizenship. A biocitizen is necessarily gendered. The cases presented in the preceding chapters point to ways in which individuals both affirm and resist norms of gender and health. Their narratives of integrity and authenticity draw on the imperatives of biocitizenship. These narratives show the link between identity, embodiment, and the ability to be recognized as a whole person in social interactions. It is this intersection of gender, identity, embodiment, and social recognition that social bio-legitimacy attempts to encompass. Future research needs to address the medical interactions of biocitizens and opportunities for resistance to cultural expectations about health and gender. Additionally, the relationship between health and gender as understood through the mutual processes of subject formation and gendering by virtue of the centrality of the body, requires a return to feminist health research. Social bio-legitimacy begins at the interactional level and uses the body as the thread tying together multiple levels of the gender system while connecting ideologies of gender with ideologies of health. Resistance becomes an embodied act as subjects negotiate health care and health behaviors.

Case Summary/Comparison

Medical care presumes a particular alignment of gender identity, body, and treatment. When these components are out of alignment medical practitioners must either alter the treatment plan, the treatment interaction, or the patient's body. When the misalignment is the result of a "natural accident" like male breast cancer, then practitioners may take steps to alter the treatment and interaction for patients in order to preserve the normative alignment between identity and body. This was evident in the accounts of cisgender men whose interactions in the course of treatment revolved around "protecting" women patients from the presence of men in a clinical space defined by femininity and by attempts to normalize men patients through the use of different colored gowns and language affirming that men get breast cancer too. Transgender men, although also seeking care in woman-centered spaces, had a markedly different experience than cis men. Trans men described their struggles with bodily terminology and gynecological care that facilitated altering their bodies through hysterectomy. Rather than medical care that affirmed their identities as men, trans men generally experienced care that questioned their identities or problematized their bodies.

The comparison between cis women who live flat and those who choose breast reconstruction reflects similar patterns of medical scrutiny for those patients who choose to alter their bodies in ways that resist normative expectations for gendered bodies. Cis women who are BRCA positive, like cis men with breast cancer, simply have medical bad luck and the role of the physician is to correct this misfortune through surgical interventions, chiefly mastectomy and breast reconstruction. The “accident” of a genetic anomaly (BRCA) and the standard treatment (bilateral prophylactic mastectomy) intervene in the expected alignment of patient identity and body. Because this treatment is considered medically necessary, the logical next step is to engage in an additional intervention to re-align body and identity with ideologies about what a woman’s body should be. Cis women who choose prophylactic mastectomy against prevailing medical wisdom have, like trans men, chosen to alter their bodies in ways that disrupt the expected identity-body-ideology relationship. When providers acquiesce, they expect and encourage women to have breast reconstruction. A patient’s disinterest in this procedure may mark her as suspect and troublesome.

Let me be clear, these differences are not simply a matter of medical evidence or the objective assessment of medical risks. Often the medical treatment is in opposition to medical evidence (i.e. recommendations for trans men to have hysterectomies simply because they are uncomfortable with gynecological exams), is conducted without medical evidence (i.e. breast cancer treatments for cis men when all research has been conducted with cis women), or is supported by studies purporting to be objective yet are heavily influenced by the status quo of gender (i.e. the greater evidentiary weight given to studies explaining the psycho-social benefits of breast reconstruction compared to studies reporting that flat women are just as satisfied after mastectomy). The cycle of care for breast and gynecological cancers (and potentially other illnesses) is ideally a balance between evidence-based medicine and patient-centered care. The experiences of cis women who live flat and trans men compared with those of cis women who reconstruct and cis men, suggest that decisions about cancer care for breast and gynecological cancers are not suitably explained through these principles. Instead, these cases show that medical evidence and a provider's willingness to defer to patient wishes support care decisions that shape patient bodies in accordance with normative ideologies of gender. My research indicates that care decisions made by both patients and providers are largely shaped by commonly held beliefs about what it means to be a woman or a man and how those meanings map onto and shape the physical body. These beliefs, on the part of providers, shape gender. Gender is not a variable determining access to care and health outcomes nor is it an individual attribute. Instead medical practices are embedded within the gender system and as such are influenced by cultural ideologies of gender. Medical care is both shaped by ideas about gender but also reproduces those beliefs through the bodies of patients.

Practical implications

Health and medical care are critical arenas for the study of gender. Theoretical approaches to this topic must be able to account for gender as more than a category of difference because health become central to American social life. The idea of social bio-legitimacy attempts to merge scholarship on biopolitics and biocitizenship with theories of gender and health. Gender identity and health are intertwined both for patients and for medical providers. With the advent of gender-specific medicine, a better understanding of how medical care bolsters or threatens the gender structure is imperative to improving access and freedom of decision making for patients.

It remains essential to bring relational theories of gender to bear on clinical practice. This does not mean abandoning other research utilizing gender as a binary category in order to better understand various therapeutic treatments and the trajectories of disease. Rather this research must occur in a context that clearly delineates the situatedness of biomedical practice (both research and clinical care) within the gender system and other social structures that lead to inequality. Additionally, medical practitioners need to be trained in relational theories of gender with a clear explanation of how taken-for-granted gender ideologies shape clinical judgment and the power that health care providers have in maintaining and challenging structures of inequality through medical practice. This is an opportunity not just for sociologists to train health care providers. It is an opportunity for innovative collaborations between medical and social researchers to improve our understanding of the complexities of health care and the role of health care in maintaining (and potentially changing) the cultural system of gender. This research would also help to add rich empirical data to ongoing feminist debates about gender and the body.

The addition of a sociology section to the Medical College Admission Test (MCAT) provides an opportunity to bring sociological concepts to future physicians and other pre-health students in a way that moves beyond bio-medical interest in cultural competence but to mentor students to grapple with medicine's embeddedness within the gender structure (as well as structures of race and class) and the social imperative to be always accountable to normative expectations of gender. This imperative applies equal pressure to health care providers and patients. The recent changes to the MCAT have the potential to bring pre-health students into sociology classrooms where in prior years these students may have prioritize hard science courses to prepare for their chosen profession. There is an opportunity here to not only to aid future medical students in passing a standardized test, but to help them begin to question the underlying assumptions of medicine and the embeddedness of the profession within social systems of difference. Additionally, as patients, our students (whether they are pre-health professionals or not) need to be aware of the ways that the gender system shapes their care. In so doing, they can be more active participants in their care. This in turn can bring about eventual changes to the gender system.

These broad implications suggest a specific avenue for future research within the context of female cancers. In order to provide a more nuanced understanding of social bio-legitimacy (the ways in which ideologies of gender and health shape and are shaped by bodies through interactions between patients and providers) it will be necessary to explore provider narratives of care for the patient groups identified in my research. I have described *patient perceptions* of these encounters, an approach that prioritizes the lived experiences of those who must bear the consequences of medical decisions in their everyday social lives. Investigating these scenarios with medical professionals will help to identify how implicit or explicit ideologies of gender are in health care. Additionally, I suggest that a thorough investigation of these concepts in the context of medical education will be instructive in identifying points throughout the physician curriculum where ideologies of gender can be removed from the shadows of physician education and allow future physicians to grapple with normative expectations for patient bodies while critically examining what is meant by health when treating patients.

Concluding Thoughts

Medicine is an important social institution with ramifications for the social structures that organize social life. Medical interactions require categorizing bodies as ill or healthy, normal or pathological, treatable or untreatable. As a result, the production of medical knowledge and the provision of health care are based upon and reinforce definitions of normal bodies. In this manuscript I have argued that this categorization, like most everyday interactions, begins with a determination of gender. The process of doing and determining gender within the medical context is especially fraught because bodies are explicitly on display in ways for which previous theories of interaction are unable to account. Additionally, these medical interactions involve a process of legitimation where medical providers and patients are engaged in maintaining and resisting the gender system.

As I show in this dissertation, this system can be threatened in two ways. The first is by an "accident of nature" that alters the body. This is the case for cisgender men diagnosed with breast cancer and cisgender women diagnosed with BRCA. Medical providers target their treatment plans not only to address illness and restore the body to a state of health, but also to restore the dignity of gender that these diagnoses threaten. The second threat to the system is through patient choice that are perceived by physicians as willful disregard of normative treatment and normative expectations of gender. When transgender men follow medical advice and seek gynecological care and when cisgender women elect to have contralateral prophylactic mastectomies after a breast cancer diagnosis and then choose to live flat, they confront a medical system that is confounded by them. These patients, though their decisions are based in a desire to be healthy, disrupt the alignment between identity, body, and gender ideologies upon which medical care relies. In order to move beyond the binary assessment of gender in biomedicine, we must dig deeper to understand how the system of gender operates on and through medical care.

Appendix: Methodology

I often say that this research began as I tried to make sense of two concurrent events: the gynecological issues of a transgender friend and a controversy over a homophobic email sent out by a few students at the socially progressive medical school attended by my spouse. The larger story is that these events made me question why it is that as a gender non-conforming person I avoid preventative medical care and only seek care when I have a sports related injury (i.e. a sprain, a broken bone, etc.). The only exceptions are at the urging of an intimate partner. In point of fact, all my gynecological care is the result of this type of pressure. One event in particular drives this study. A decade ago, a nurse practitioner (NP) expected to perform a pelvic exam and pap smear during my annual physical. I had no idea that this was happening before the visit (presumably most female-bodied individuals understand that this is a standard and expected component of a regular physical). Upon entering the exam room, I saw the speculum and Aylesbury spatula (only the third time I'd ever encountered these instruments) and promptly began to panic. I worked hard to conquer the growing (and I thought) irrational fear of what was to come, only to break down in tears as the NP approached. She was visibly bewildered and asked if I'd been the victim of sexual abuse.

This framing, that discomfort and fear of a pelvic exam could only be explained by past sexual abuse, deeply troubled me. I began connecting my personal experience of medical care as a female-bodied, masculine presenting person with the concerns in the medical school about improving student understanding of sexual and gender diversity and with my transgender friend's gynecological issues. There is something uncomfortable about the relationship between how medicine is practiced and the management of patient identity. These two concepts are often at odds in care. While few women actively enjoy gynecological exams, many accept it as part of what it means to be a woman, though plenty of exceptions are possible. Several queer identified women avoid gynecological care due to personal discomfort with having foreign objects inserted into that part of their bodies. This is distinct from studies that indicate that queer women avoid this type of care because they fear discrimination by providers based on their sexual identity. While this discrimination is very real, it does not account for all the reasons individuals avoid gynecological care. Rather, we must also identify how we, as patients, understand our bodies, identities, and health care. Certainly discrimination (and fear of discrimination) based on gender identity and sexuality in medical care are real, but I think there's something else going on when queer patients consider medical care. What specifically is the relationship between gender identity and medical care? My focus on gender identity is meant to add to current research concerning discrimination in health care based on sexual identity. I believe that while this research is essential, it fails to address the additional complications of normative gender for health care. The puzzle is this: who I am is more than my body, but it is also deeply my body. How patients and providers navigate this puzzle is central to the adequacy of care that patients receive.

Epistemological Considerations

Central to my research design is the notion that cancer queers the body. In their introduction to *Queer Methods and Methodologies*, Kath Brown and Catherine J. Nash note the impossibility of defining queer or of identifying unifying patterns of queer methods, thus understanding as queer any scholarship that "highlight[s] the instability of taken-for-granted meanings and resulting power relations" (2010, 4) and, perhaps more importantly, "seeks to subvert, challenge and critique a host of taken for granted 'stabilities' in our social lives" (2010, 7). Gynecological and breast cancers have the effect of disrupting many of these stabilities including mortality, gender identity, and the integrity of the physical body. A queer methodological approach helps to unravel the ways in which patients understand their experiences of these cancers.

Central to this queer approach to research is the importance of telling stories that reflect the everyday sense making in which all individuals engage. The premise of this story telling is the assumption that gender and sexuality are not fixed, that identity is fluid and in a constant state of becoming, but that gender and sexual identity serve as stabilizing forces for individuals and social life in a given moment. Rooke states that the power of ethnography lies in its potential to shape theory "by offering knowledge of the world in practice: the way that people make sense of the understandings available to them. It is a way of grounding theoretical comprehension in a located social context" (2010, 27). For Rooke, queer ethnography is uniquely situated to do "justice to the ways that people live their gendered and sexual subjectivities with complexity" (2010, 39).

I am equally influenced by feminist epistemologies. Hesse-Biber, Leavy, and Yaiser suggest that feminist research, although diverse in approach and methods, “is attentive to issues of difference, the questioning of social power, resistance to scientific oppression, and a commitment to political activism and social justice” (2004, 3). Further, feminist research tends to privilege the everyday experiences and understandings of actors (specifically women) in the creation of knowledge. This is based in the widespread feminist acceptance of the existence of multiple subjectivities rather than universal truth.

More specifically, this study is located within the tradition of feminist standpoint theory (Harding 2004a and 2004b; Zalewski 2000), which argues that knowledge is shaped by gender (amongst other social factors) and that undertaking research from the perspective of marginal social groups can advance knowledge; a view of research which developed in direct contrast to positivist scientific research which separated knowledge from the social context in which it was produced (Harding 2004a; Hesse-Biber, Leavy, and Yaiser 2004). For standpoint theorists, traditional scientific approaches to knowledge are inadequate for identifying and addressing social concerns. Further, feminist standpoint theory is rooted in the Hegelian idea that the oppressed have a dual perspective: that which is developed through experience and that of their oppressor which they develop to survive (Hesse-Biber, Leavy, and Yaiser 2004). Thus, starting research from the perspective of marginalized people allows researcher to examine the marginalized groups (common in the past) and the lives of the dominant group. These differences are based in structural differences in society that position some groups as dominant and others as marginal. Harding (2004a) argues that starting from these perspectives provides new and more critical questions about the social order than starting research from a dominant perspective.

The importance of narrative

In order to focus on the sense making strategies of individuals outside the dominant discourse of cancer care and in keeping with the queer methodology discussed above, I employed a narrative approach to research. According to Popay and Groves (2000), the master narrative produced by epidemiological and medical sociological research of "men die, women get sick" relies too narrowly on outdated sex role theory, ignores gendered experience, and ignores the historical context in which the relationship between gender and health occurs. They argue that research into the relationship between gender and health needs to disaggregate gender (in contrast to standard epidemiological approaches) and better attend to the relationship between social structures and agency.

The method for doing this, they argue, is through narrative research. They posit that too much research into gender and health has been conducted through quantitative means. This has produced a great deal of insight, yet has been unable to yield an understanding of how the gender structure leads to gender inequalities in health. This research also fails to bring to light issues of subjectivity, personal experience, and individual identity. The power of social structures is overemphasized thus limiting a full understanding of how social structures impact health as a relational process. For Popay and Groves, the power of narrative research follows from that of qualitative research as a whole which by "focusing on the accounts that people give of their daily lives and health experiences, offers a means of exploring the relationship between agency and structures" (2000, 64). Within qualitative research, a focus on narratives provides the key point of entry to an analysis of subjectivity because this approach allows individuals to tell about the multiple and fluid social locations they occupy, and why they change across time and place and the salience of these for their lived experience (Popay and Groves 2000, 77). Further, they argue that these narratives provide insights into the way in which individual identity, experience, and action are gendered (Popay and Groves 2000, 77). Narrative accounts create a reflexive space because by creating a narrative an individual "(re)construct[s] their sense of who they are in the context of the social and material world and biographical and historical time. Narrative accounts of experience illuminate the subjectively experienced relationship between identity (people's sense of who they are), agency (an individual's capacity for action) and social structures (macro mechanisms and processes by which power and control are socially distributed and utilize) which impinge on the ways in which individuals negotiate and live their lives" (Popay and Groves 2000, 76). The narrative approach addresses some major methodological issues of health related gender research, specifically a lack of understanding of bodily experiences in lieu of epidemiological uses of gender as a variable which structures disease outcomes by virtue of gender role behaviors and access to care.

The use of narrative data does have certain limitations. Popay and Groves admit that there is not enough research to date to prove their claims about the power of narrative research in the study of gender and health (2000, 78). Narrative accounts are also always constructed within a normative conversational context, thus calling into question the accuracy of the speaker's statements. Despite these criticisms, the normative aspects of conversation and the social pressure to be accountable to social norms may actually illuminate the ways in which individuals attempt to make sense of personal experiences in light of normative social pressures in order to create social and individual identity. This balancing of personal experience and social structure is part of the process of subjectivity. What narrative research may accomplish is bringing unconscious work done by individuals regularly into public view. Further, the use of narratives is increasingly important in debates about medical ethics (Charon 2006; Charon and Montello 2002; Charon and Wyer 2008; Childress 2002; Frank 1995; Williams 1984). Utilizing this approach merges contemporary concerns of the medical profession with innovative sociological research, thus creating a shared language between the two fields.

Arthur Frank in particular was a proponent of this type of interviewing for health experiences because he argued that a key component in the process of recovery was the reconstruction of the self through narrative. "A self that has become what it never expected to be requires repair, and telling autobiographical stories is a privileged means of repair… though hardly the exclusive means" (Frank 2000, 135). As Sulik has shown with breast cancer, identity and the narrative individuals tell about their experience of illness is central to the recovery process. It is this narrative construction that so many feminists find objectionable (for example

Ehrenreich 2001 and 2010; Hess-Biber 2014). Frank notes that the purpose of narrative or life history interviewing as a method for understanding health and illness requires “describing how ill people's selves are the effect, not the cause, of their stories, how these stories can be credited or discredited, and how stories are constructed from culturally available rhetorics” (Frank 2000: 136). As such, centering research on the narratives told by individuals provides insight into how gynecological and breast cancer diagnoses and related health care impact patient identities, how available rhetorics of gender shape that impact and the narratives patients tell as part of the repair process.

Following in this tradition I began interviews in as open a fashion as possible drawing inspiration from life history interviews. Such an interview allows respondents to craft their own account of their experiences and the meanings derived from them, thus allowing respondents to participate in the act of theorizing (Heckert 2010; Weiss 1994). Rather than searching for "true experience," interviews provide insight into the processes by which individuals understand themselves and their social worlds, as well as how those social worlds come into being thus aligning with Connell's argument that body reflexive practices create social worlds (2005). Rather than using survey style interviewing or an actual paper survey to collect demographic information from participants I instead asked them to tell me a bit about themselves. I gave some examples such as their age, race, and how they spend their days. I often followed this up with a question about whether they live with anyone else. These open questions allowed participants to describe their demographic characteristics in their own terms. Often greater detail was provided during the course of the interview as they told me about their support networks and family history in relation to their diagnosis and health care decisions.

Narrative inquiry remains an emergent method in social research. Chase characterizes narrative as "a distinct form of discourse: as meaning making through the shaping or ordering of experience, a way of understanding one's own or others' actions, of organizing events and objects into a meaningful whole, or connecting and seeing the consequences of actions and events over time" (2011, 421). She notes that narrative inquiry is particularly useful in exploring identity construction, specifically "whether people's identity constructions through storytelling reveal the self's unity, multiplicity, or both; how self and society contribute to people's constructions of narrative identity; and how people's stories display stability, growth, or both, in their identities" (Chase 2011, 422). In his introduction to a special edition of the journal *Qualitative Sociology,* Zussman states: "Narratives constitute the self" (2001, 5). As I am concerned in this research to explore how individuals negotiate gender identity through the bodily experience of gynecological and breast cancer, narrative inquiry is well suited to allow participants to construct their own stories and build their own theories of gender.

Chase notes that narrative inquiry "requires a shift from the conventional practice of asking research participants to generalize about their experiences… to inviting narrator's specific stories" which also requires that the interview schedule does not structure the interview and guide analysis. Instead the narrative itself becomes the guide to the analysis (Chase 2011,423). Riessman (2001) notes that in narrative inquiry it is the story itself that is the object of inquiry. Rather than an interview wherein the researcher asks a series of predetermined questions, which may prompt the participant to reflect in a somewhat disjointed way, narrative interviewing requires soliciting stories (as opposed to answers) and allowing the participant to construct the flow of the story. Analysis of such data, then, centers on understanding why a participant's story was told in the way that it was (Riessman 1993). Narrative analysis thus requires attention to how a story is told as much as to the content of the story.

One of the most powerful aspects of narrative interviewing is that these are moments not only when the interviewee provides an account of their experience, but they “explain one’s conduct to oneself” (Irvine 2000, 12). In other words, in telling the story of their illness or health care experience, my research participants engaged in a reflexive process where they not only reported their experiences, but accounted for these stories and constructed a version of themselves. Importantly, Irvine situates this identity work within the context of institutions (Irvine 2000,11). This contextualization allows me as a researcher to begin to theorize about the medical regulation of gender in terms of patient identities and patient bodies.

Sample

I initially designed this study with a focus on gynecological care and breast cancer. As I began recruiting through internet groups, young women with BRCA diagnoses began contacting me about participating. This was not an experience I initially considered but I did add this case due strong interest in participating by BRCA positive women. They provided a useful link between the experiences of transgender men with preventive gynecological care and cisgender women with breast cancer. Women with BRCA who contacted me were engaging with preventative breast cancer care in ways similar to transgender men with gynecological care. At the same time these women were working through the same kinds of decisions as women with breast cancer regarding mastectomies and reconstruction.

Details about participants in each of the case studies are provided below. Each participant has been given a pseudonym. In general participants in this project were well educated (46 held degrees beyond high school), comfortably employed, and white. Given the difficulty presented in recruiting individuals from the populations under study, I was unable to ensure that my sample reflected a wide range of racial/ethnic groups and socio-economic classes. It is evident that the intersection of a range of social markers are important in understanding issues as complex as the medical regulation of gender and access to/ability to navigate within the U.S. health care system. However, part of the value of this sample is exactly the fact that the majority of respondents are white, middle/upper class individuals. These are the people who *should* have the most access, the most financial means, and the greatest ability to have their desires and interests about their bodies heard and respected by health care providers. Instead in these stories there is a range of experience from extremely positive to heart-wrenchingly negative. Furthermore, these experiences do not easily map onto social categories like age or class.

Trans Men

13 transgender men participated in this research. These men were initially recruited through a snowball sample beginning with personal contacts who are transgender. I also fostered a relationship with a regional FTM support group and participated in transgender health conferences in New England. My gender non-conforming identity allowed me access to the support group and marked me as a sympathetic listener to those who agreed to participate. Upon connecting with the FTM support group I made it plain that I was a researcher in order to avoid any impression of dishonesty. Participants ranged in age from 23-61. All but one participant had experienced some kind of gynecological care; either routine screenings or treatment for a specific condition. Five of the participants had hysterectomies at the time of interview and three others were seriously considering this surgery primarily for non-medical reasons.

Table A.1 Transgender men					
Name	**Age at interview**	**Received care Y/N**	**Had hysterectomy (Y/N)**	**Education**	**Marital Status/ Children**$^{+}$
Joe	36	Y	N (considering)	Bachelors	M/Y
Chris	23	Y	Y	High School	S/N
Gabe	61	Y*	Y	Bachelors	D/Y
Evan	60	Y	N	Bachelors	S/N
Erik	32	Y	Y	Bachelors	S/N
Kevin	26	Y	N (considering)	Masters student	S#/N
David	53	Y*	Y	Masters	D/Y
Jamie	27	Y	N	Masters	S#/N
Eli	33	Y	N	Bachelors	S/N
Zach	24	N	N (considering)	Bachelors	S/N
Isaac	33	Y	Y	Doctoral	S#/N
Noah	32	Y	N	Bachelors	S/N
Peter	33	Y	N	Masters	S#/N

**indicates participant gave birth*
+M= married, S= single, S#= committed relationship, D= divorced, Y= has children, N=no children

Cis men

11 cisgender men agreed to share the experiences of breast cancer. Participants ranged in age from 28-71, had at least an undergraduate degree and were white. All but one man was married or in a committed partnership at the time of the interview. I recruited cis men at breast cancer conferences and by posting calls for participants in online forums for men with breast cancer.

Table A.2 Cisgender men				
Name	**Age at Dx**	**Age at Interview**	**Education**	**Marital/ Parent Status**
Ed	70	71	Masters	M/Y
Tim	24	28	Bachelors	S/N
Frank	55	62	Bachelors	M/Y
Ted	54	55	Masters	M/Y
James	60	61	Masters	M/Y
Larry	62	66	Bachelors	S#/N
Ezra	46	47	Doctoral	M/Y
Owen	57	66	Bachelors	M/Y
Mark	65	67	Doctoral	M/Y

Table A.2 Cisgender men (cont.)				
Name	**Age at Dx**	**Age at Interview**	**Education**	**Marital/ Parent Status**
Henry	53	55	Doctoral	M/Y
Mitch	51	51	unspecified	M/Y

+M= married, S= single, S#= committed relationship, Y= has children, N=no children

Cis Women

Over the course of this project I interviewed 20 women who had been diagnosed with breast cancer and treated with mastectomies and 13 women who tested positive for BRCA but did not have breast cancer. I began recruiting participants at breast cancer conferences in New England and via personal contacts. Often when an acquaintance learned about my dissertation topic I would be referred to a friend who had completed treatment. Although I initially set out only to interview women who were diagnosed with breast cancer and chose to undergo bilateral mastectomy, BRCA positive women approached me when I posted calls for participants to online venues frequented by both "previvors" (women diagnosed with BRCA) and women with breast cancer who chose mastectomies. The women in these groups are unique in the cultural story of breast cancer because they chose bilateral mastectomies whereas other women (due to the particulars of their diagnosis) may not have this option. 11 of the BRCA positive women have had or planned to have breast reconstruction. Of the two women who live flat[1], one experienced a failed reconstruction and chose to live flat following those complications. Of the 20 women interviewed with breast cancer, four currently have reconstructed breasts. One of those women is considering a "deconstruction" or removal of the implants. The other 16 women

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[1] This is a term used by women to describe themselves and others who have undergone mastectomies and choose not to have reconstruction. During interviews, participants regularly referred to their decision to "live flat." This term has even become mainstream as women who live flat are becoming more visible (see http://www.breastcancer.org/treatment/surgery/reconstruction/no-reconstruction).

live flat. Of that number, two women initially chose to reconstruct breasts and experienced complications that led them to live flat.

Table A.3 BRCA positive women						
Name	**Age at Dx**	**Age at Interview**	**Reconstruction (R) or Flat (F)**	**Education**	**Marital/ Parent Status**	**Hysterectomy/ Oopherectomy**
Julie	30	31	R (planned)	Doctoral	S#	N
Jody	28	29	R	Bachelors	M/N	No
Alyssa	36	36	R	Masters	M/N	N
Michelle	22	28	R	Bachelors	S	No
Emily	18	22	R	Bachelors	S	No
Madison	24	28	R	Bachelors	S#	No
Julia	33	34	R	unspecified	M/Y	No
Katie	37	45	R	Masters	M/Y	Oopherectomy
Sally	33	35	F	Masters	M/Y	Planned
Nicole	28	32	R (planned)	unspecified	M/Y	Hysterectomy
Margaret	43	43	R	Bachelors	M/ Y	Hysterectomy
Liz	29	36	F	unspecified	M/Y	Both
Kathy	54	54	F	Masters	M/Y	Oopherectomy

+M= married, S= single, S#= committed relationship, D= divorced, Y= has children, N=no children

Table A.4 Women with Breast Cancer					
Name	**Age at Dx**	**Age at Interview**	**Reconstruction (R) or Flat (F)**	**Education**	**Marital Status/ Children**
Kate	36	46	F (failed reconstruction)	Doctoral	M
Fran	52	70	F	Doctoral	M
Linda	60	63	F	Some college	S
Sandy	58	59	R	Bachelors	M
Karen	36	39	F	Doctoral	M
Edie	47	50	F	Bachelors	M
Colleen	24	34	R	Doctoral	M
Ellen*	38 (most recent)	56	F	Bachelors	M
Sadie	63	64	F	Masters	S/N
Ashley*	38, 40	41	F (separate mastectomies for primary cancers)	unspecified	M
Samantha	45	57	F	Bachelors	M
Suzy*	54	54	F (one side)	Doctoral	S/N

Table A.4 Women with Breast Cancer (cont.)					
Name	**Age at Dx**	**Age at Interview**	**Reconstruction (R) or Flat (F)**	**Education**	**Marital Status/ Children**
Lorie	49	51	R (considering deconstruction)	Some college	M
Maggie	41	43	F	Doctoral	M /Y
Catherine	34	36	F	Bachelors	M
Judy*	45, 50	50	F	unspecified	M
Alison	31	32	F	Doctoral student	M
Rachel	36	50	F	Some college	M
Sam	41	43	F	Masters student	M
Clare	35	39	R	unspecified	M/Y

*diagnosed with breast cancer twice

+M= married, S= single, S#= committed relationship, D= divorced, Y= has children, N=no children

Interviews

Interviews were conducted in person, over the phone, or via Skype/FaceTime depending on the location of the participant and his/her technological preferences. Interviews that were within driving distance (no more than 2 hours) were conducted in person whenever possible. The broad geographic range of participants, including a few international participants who had been treated while living in the US, precluded face to face interviews. Skype and Facetime both provided a degree of face to face contact thus promoting trust between myself and the participant. For those who chose phone interviews, they either did not have access to technology that would promote long distance face to face interviewing or they preferred the anonymity offered by a phone call. The quality of phone interviews was not substantially different than those conducted face to face. In some cases, participants followed up our conversation by emailing photographs or referring me to their blogs or Facebook pages in order to illustrate the story they told.

Interviews ranged from 45 minutes to 2.5 hours and were largely unscripted. Because I was interested in the ways in which participants constructed their identity via the narrative of their cancer experience, I utilized life history interviewing techniques (Atkinson 1998). Participants were first asked to tell me a little about themselves along with the suggestion that they include their age, how they spent their days, and who they live with. This opening was sufficiently open ended to allow participants to describe details about their lives that they felt were relevant while also giving them time to get comfortable talking about themselves. Each participant was then asked to imagine that they were crafting a novel or screenplay about their experience with gynecological care, breast cancer, or BRCA and to describe the opening scene of that story. This began the interviews with a focus on the telling of a story about cancer, thus providing rich data with which to understand how patients made sense of their experience. From there, the interviews followed a conversational flow where I asked follow up questions based on the story as the participant told it. At the end of the interview, participants had the option to share any questions that they had for others with this experience. I then integrated those questions into subsequent interviews as follow up questions when appropriate and as scripted questions if the opportunity did not arise during open conversation. Interview data thus represents my methodological orientation to narrative inquiry and my commitment to ensuring that the results of this study are meaningful to both the participants and to others facing these decisions. This sequential interviewing technique allowed me to determine a point of saturation within each category of experience (Small 2009).

Interview data was transcribed either by myself or by Matchless Transcription LLC. A grant from the University of Chicago Social Sciences Division funded the transcription and the purchase of data analysis software. Quotations have been edited for clarity but remain as close to verbatim as possible to retain the voice of individual participants (Weiss 1994).

Analysis

Transcripts were imported into NVivo 10 for Windows and were coded inductively to identify emergent themes and to allow the relationships amongst narratives to emerge (Coffey and Atkinson 1996; Marshall and Rossman 1995; Patton 2002; Ramanzanoğlu and Holland 2002). Coding began immediately following the interviews, as I analyzed my field notes for patterns and questions that I wanted to ask in future interviews. Each interview transcript was then coded individually and compared to the analysis of my field notes. Once all transcripts had been coded separately, I read through the transcripts again with a master list of 48 codes. At this point I identified the major themes in each case study and using NVivo grouped sections of text based on the relationships between codes. This coding strategy is built upon conventional content analysis as described by Hseih and Shannon (2005). This method requires several readings of each narrative. Each is first read (multiple times) as if a novel (that is as a self-contained story). Narratives are then re-read to identify words in the text that may serve as codes linking one narrative to another. Additionally, through the use of my field notes taken during and just following interviews, I was able to track my impressions of the narratives, thus creating a reflexive component to the analysis. These codes (reflecting both the language of the narratives and my initial impressions and analysis) are then sorted into categories in order to explain the relationships not only between the narratives but between the codes as well.

My approach to data analysis is also informed by a queer epistemological understanding of subjectivity.

> Queering subjectivity requires rethinking credibility in terms of the way that all narratives are told in circuits of social power… the crux of 'queer' within the

> social relationships of conducting research is therefore twofold; for the queer scholar it becomes a case of remaining alert to how subjectivities are an outcome of a relational process and to how a queer methodology must facilitate telling and interpreting narratives that do not inadvertently impose meanings rather than seeking to rework and create new meanings. … How narratives are told frames how meanings are shaped (Gorman-Murray, Johnston, and Waitt 2010,101).

Although I coded inductively, in my analysis I was cautious about uncritically reporting respondent's narratives. By attending to the ways in which the narratives of participants are embedded within structures of social power and how the experiences of participants stand in conversation with theories of gender, embodiment, health, and beauty I am also able to address Hseih's and Shannon's concern that inductive coding may fail to include a complete understanding of the context of the narrative and the difficulties of establishing the theoretical relationship between analytical codes.

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