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### From decision to incision: Ideologies of gender in surgical cancer care

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## **From Decision to Incision: Ideologies of Gender in Surgical Cancer Care**

### **Abstract**

In this paper, I draw on the narratives of 57 individuals whose gender identities and decisions about their bodies trouble the medical protocols for breast and gynecological cancer care. I focus here on the decision-making process for three groups of elective surgeries: hysterectomy, prophylactic bilateral and contralateral mastectomy, and breast reconstruction. These elective surgeries illustrate places in medical interactions where patients and providers rely on frames of gender to determine whether a given surgery is an appropriate option for cancer prevention or care. These cases also explain how patient experiences of medical interactions are shaped by and thus reproduce ideologies of gender through the bodies of patients. While clinical practice and medical decisions are supposedly determined through the principles of evidence-based medicine and patient-centered care, I show that ideas about gender can actually supersede both medical evidence and patient desires for their bodies in the care of gynecological and breast cancers.

**Key Words:** gender, cancer, embodiment

### **Introduction**

The medical profession has a gender problem. In 2016, National Public Radio (NPR) and *The Atlantic* brought public attention to research suggesting that the patients of women doctors have lower mortality rates than patients of men doctors (Hamblin 2016; Schumann and Schumann 2016; Tsugawa et al. 2017). The media and social media attention to these findings highlighted assumed differences between men and women. An editorial by physicians Parks and Redberg (2017) suggested that the improved outcomes documented by women physicians hinge on communication style, length of time spent with patients, and encouraging patients. Each of these characteristics is tied to stereotypical ideas about what it means to be a woman in society. This study and the brief flurry of attention it received introduce the complexities of the relationship between health outcomes and the importance of normative (and taken for granted) expectations about gender to medical decision making.

In this paper, I draw on the narratives of 57 individuals whose gender identities and decisions about their bodies trouble the medical protocols for breast and gynecological cancer

care through the decision-making process for three groups of elective surgeries: hysterectomy, prophylactic bilateral and contralateral mastectomy, and breast reconstruction. These elective surgeries illustrate how patients and providers rely on frames of health and gender to determine whether a given surgery is an appropriate option for cancer prevention or care. These cases thus explain how medical interactions are shaped by and reproduce ideologies of gender through the bodies of patients. While clinical practice and medical decisions are supposedly determined through the principles of evidence-based medicine and patient-centered care, I show that ideas about gender can actually supersede both medical evidence and patient desires for their bodies in the care of gynecological and breast cancers.

### **Conceptual Framework**

Normative ideologies of gender are evident in two key areas of medical practice: medical research and in the clinical setting where patient care occurs. In the 1960s, activists in the Women's Health Movement and academic feminists began to question the reliance on men as clinical research subjects and to point out gender-based disparities in health care access, outcomes, and the profession itself (see Ruzek 1978). To address these problems, activists advocated for a shift to patient-centered care and for establishing gender as a key variable in evidence-based medicine (see Claridge and Fabian 2005; Armstrong 2007; Epstein 2007; Sur and Dahm 2011; Bardes 2012; Mazure and Jones 2015).

Evidence-based medicine is a relatively recent development within health care, originating in the 1960s but not becoming standard in the field until the 1990s (see Claridge and Fabian 2005; Sur and Dahm 2011). Evidence-based medicine practices call for clinical decisions to be based on the findings of clinical and laboratory research. Until the 1990s, this research was conducted primarily with white, male subjects. Critiques of this model led to the adoption of 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 where 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.

There-in lies the gender problem for medicine. The medical community understands gender as a binary variable impacting outcomes and has incorporated this binary view into the practice of evidence-based medicine. Critics argue that this approach ignores the sociological understanding that gender is a set of social processes thus ignoring the structural, rather than individual factors that impact health (see Annandale 2009, Connell 2012; Hammarström et al. 2014; Springer, Hankivsky, and Bates 2012).

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). That is, patients are meant to have input and power in the health care they receive. Patient-centered care, however, turns on an expectation that patients behave as good biocitizens. 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 men and women*" (Rose 2007, 132, emphasis added). The inclusion of gender as a variable in clinical research links normative

expectations of gender to the empirical basis of biocitizenship. Social life and medical care are thus both characterized by *beliefs* about men, women, and their respective bodies that are relational, controllable, and transformable primarily through medical interventions (including clinical interactions). 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.

Decisions about elective surgery in the case of gynecological and breast cancer highlight tension between the foundational principles of clinical practice and the responsibilities inherent in biocitizenship. In the context of gynecological and breast cancers, ideologies of gender become central in resolving this tension. Patients who behave as biocitizens by becoming informed of their options, the potential outcomes of a given procedures, the risks involved in that procedure, and through consideration of impacts on their quality of life face obstacles in implementing their choices when they conflict with the ideologies of gender that serve as the foundation for medical practice.

Medical and popular narratives of breast and gynecological cancers turn on stereotypes of femininity and female sexuality: the "right patient" for care is a cisgender, female identified, heterosexual woman, with normative desires for her body's appearance. In order to understand how gender shapes medical decision making, I interviewed individuals whose bodies, desires for their bodies and/or gender identities don't match the medical and social expectations for gynecological and breast cancer care: transgender men (N=13), cisgender men (N=11), and cisgender women (N=33) who choose prophylactic mastectomy after a breast cancer or positive BRCA diagnosis.

I conducted in-depth, narrative interviews to explore the details of participants' experiences and how they made sense of these experiences. Interviews ranged from 45 minutes to 2.5 hours and were conducted in person, via Skype or FaceTime, and over the phone. Participants ranged in age from 22-71. Among the trans men participants, 5 men had undergone hysterectomies (1 prior to transitioning) and 3 were considering the surgery. All of the trans men who participated in the study were aware that hysterectomy was a medically approved option even when they did not consider it a personal option. I did not specifically solicit information from trans male participants regarding top surgery or hormone use. Trans men and cisgender women who were BRCA positive tended to be younger (N=20 under the age of 40). The majority of cisgender women diagnosed with breast cancer refused breast reconstruction (N=14). The majority of cisgender women diagnosed as BRCA positive chose breast reconstruction (N=10) Two of these participants had breast "deconstruction," that is they initially had breast reconstruction and later reversed the surgery to "live flat" (the term adopted by cisgender women who forego or reverse breast reconstruction and thus have a flat chest rather than a chest with breasts).

I recruited participants through social media support groups for men with breast cancer, BRCA positive women, and women who decide against reconstruction or prosthetics. I also identified participants through a snowball sample beginning with people in my social networks as well as from participants in this research. This 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.

I conducted interviews in an open, narrative style (Popay and Goves 2000; Riessman 2001; Chase 2011). This allowed participants to determine the structure of how they explained their experiences of cancer care. All interviews were transcribed and coded inductively to identify emergent themes as well as to allow the relationships among narratives to emerge (Marshall and Rossman 1995; Coffey and Atkinson 1996; Patton 2002; Ramazanoğlu and Holland 2002, Hsieh and Shannon 2005). I paid close attention to how participants themselves reworked and created new meanings as opposed to imposing meaning upon them (Gorman-Murray, Johnston, and Waitt 2010). I provided each participant with a verbal consent form prior to the start of the interview. This research was approved by the Social and Behavioral Sciences IRB of the University of Chicago.

## **Results**

At various points in the cycles of “female” cancer care, doctors or patients may consider elective surgery. Each surgery involves the removal of currently healthy organs for the purpose of cancer prevention or the addition of foreign or transplanted material for the purpose of cancer recovery. These surgeries are not universally available to patients. For medical professionals, the “decision to incision” must include clinical data and consider a patient’s wishes. The experiences described by research participants indicate that ideas about gender, rather than simply evidence-based medicine or patient-centered care, play an important role in opening or obstructing access to surgery depending on whether or not the surgery aligns a patient's body, identity, and normative gender expectations.

### **Hysterectomy**

In 2011, the American Congress of Obstetricians and Gynecologists (ACOG) released official statements indicating that patients should have physical exams for body parts they have,

regardless of the gender with which these parts are associated. ACOG's recommendation also acknowledged that lack of knowledge about trans patients may make providers uncomfortable administering these exams (ACOG 2011).

Some gynecologists assume that trans men avoid gynecological exams due to extreme anxiety stemming from threats to their gender identity (Eyler 2007; van Trotsenberg 2009, WPATH 2011). Although some trans men described discomfort or dissociation during gynecological exams, all but one of the participants in this study acquiesced to gynecological exams. The anxiety described by participants was rooted less in how trans men saw themselves or in their concerns about the practicalities of the exam itself, and more in how they would be seen or treated by providers. Joe explained, "I feel pretty secure in my genitalia [but] 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." Joe's phrasing indicates that his fear is not about his identity, but about how he is perceived by others. This kind of judgment is a sign of gender trouble for the provider. Isaac explained this point further. "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). ... I think that because it's such a surprise to people it hinders their ability to function as medical professionals."

Although hysterectomy is promoted within the medical field and by some participants as a means of improving health outcomes for trans men, Gabe was concerned about the harms that can occur during the experience of surgery. As a hospital chaplain, Gabe had been in the position of advocating for trans men who were categorized as women by the hospital where they obtain hysterectomies. This meant wearing ID bracelets that categorized them as women, being placed in shared recovery rooms with women, and being verbally misgendered by hospital staff. These



kinds of experiences suggest that patient identities and bodies are not always brought into immediate alignment by this particular surgery, even if providers assume that transman desire hysterectomies. The concerns about treatment in medical settings expressed by participants in this study reflect broader trends among transgender Americans. Discrimination against transgender patients within the medical community is well documented (Grant et al. 2011; Institute of Medicine 2011; Cruz 2014). Importantly, it is not the actual medical procedure that is concerning, but rather the perceptions and resulting treatment that concerns many transgender people.

The clinical interaction between a health care provider and a transgender man may prove disruptive because patient identity, patient body, provider expectations, and the social space (defined by the expected woman-identified patient) don't align. From the medical perspective, Pap smear's are an essential component of cancer prevention, and trans men should submit to this exam in the pursuit of health. However, standards of care for trans men recognize such exams may be "intolerable" and link this intolerability to the low uptake of Pap smears among trans men. As a result, some medical professionals advocate for hysterectomy as an appropriate alternative (Eyler 2007).

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. This narrative originates in the standards of care promoted in the 1950s by physicians like Harry Benjamin, who were at the forefront of transgender medicine. Although the prevailing medical narrative advocated for changing the body, physicians willing to treat transgender patients would only consider those individuals who fit binary understandings of

gender largely to avoid malpractice suits and to fit transgender people into existing norms of gender (Meyerowitz 2002).

The wrong body narrative serves as a gatekeeping tool for medical professionals treating transgender patients. As a result, some transgender individuals use the "wrong body" narrative as discursive tool to gain access to medical services (Bettcher 2014, Prosser 1998). Medical services are thus predicated on notions of right and wrong bodies as defined by normative expectations of embodiment based on a binary understanding of the gender identity of the patient, regardless of how the individual wants to embody their identity.

Several scholars are deeply critical of this narrative and the way that it erases any embodied identity that counters a strictly binary view of gender (see Spade 2003, Bettcher 2014, Johnson 2015). In his study of transgender men, Rubin argues that trans men use the wrong body narrative to become "treatable bodies" even if this framing does not match their lived experience (Rubin 2003: 94). However, the ubiquity of this narrative delegitimizes trans men who seek gynecological care. Bettcher argues that "when public gender presentation and private genitalia are construed as misaligned, this representational relation yields the conditions for ... reality enforcement" (2014: 392). Medical professionals take on the role of reinforcing reality; that is, as physicians, their role is to rectify misalignment between body and identity as perceived by others, not the patient themselves.

When trans men present for gynecological care, be it routine or emergency, their bodies can become untreatable. Whether a transgender man identifies with the wrong body narrative or not, this is the dominant paradigm through which medical professionals understand these men. Seeking gynecological care puts transgender men in conflict with a narrative that assumes they are uncomfortable with their reproductive organs and/or disidentify with them to the point of

avoiding care. This is compounded by the fact that these organs and their care tends to cause others to identify an individual as a woman, thus unraveling the often complex biographical work transgender men have engaged in over time.

In an era of biocitizenship, individuals are expected to seek out routine preventive medical care. Trans men 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. 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. Hysterectomy thus becomes a way out of this predicament.

Joe and Isaac both had family histories of gynecological issues including cancer. For Joe, a hysterectomy was a potential solution to both his fears of cancer and his concerns about pelvic exams. Joe viewed hysterectomy as a way to ensure the positive outcome of “of not getting uterine cancer or having that risk any further and never having to undergo another physical exam again.” Like Joe, Isaac had no actual physical complaints, yet family history combined with his identity as transgender made hysterectomy an “easy sell” to his insurance company. For both men, health care providers supported hysterectomy as a reasonable option despite the lack of physical indicators presenting an empirical rationale for surgery.

Chris was in a slightly different situation. During repeated visits over several months, Chris saw his primary care physician for abdominal pain, yet the physician brushed aside his concerns. Eventually Chris saw a trans-friendly gynecologist who validated his pain. Chris explained that “[the gynecologist] 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.”

In order to prevent gynecological cancers, nine men in this study reported that physicians recommended the removal of internal reproductive organs or questioned their interest in keeping these organs. This is despite the fact that trans men are not at increased risk of cervical cancer and that factors like family history and pain are not acceptable as the sole component of the decision-making process for cis women. Cancer risk is also not a reliable indicator that hysterectomy should be swiftly pursued. BRCA positive cisgender women in this study universally explained that after testing positive, their medical teams suggested waiting on obtaining a hysterectomy despite their increased risk for developing uterine and ovarian cancers. The key consideration underlying this recommendation by providers was the assumption that women would necessarily like to become pregnant. Thus hysterectomy was delayed for BRCA positive cis women.

The recommendation by the medical community that hysterectomy is a reasonable option for the prevention of gynecological cancer in trans men illustrates the degree to which expectations about gendered bodies and assumptions about patient desires shape standards of care independent of scientific evidence. It is important to note that none of the trans men in this study asked their providers about having a hysterectomy. Rather, hysterectomies were routinely offered to trans men by their physicians even when similar circumstances would not lead to the same recommendation for cisgender women. For cis women, clinicians require a documentable finding upon clinical evaluation (e.g. fibroids, endometriosis, pelvic support problems, abnormal uterine bleeding, chronic pelvic pain, gynecological cancer). Upon these findings, clinicians embark on an additional series of tests and questions to ensure that hysterectomy is the best (and only) clinical decision to relieve the pain (Lefebvre et al. 2002; ACOG 2017). Like some trans men, many cis women are deeply uncomfortable with pelvic exams and pap smears, yet they are

not given the same option for surgery as are trans men (Seymore et al. 1986; Bates, Carroll, and Potter 2011).

For trans men, the path to hysterectomy is straightforward. If the patient is uncomfortable or the insurance company will easily cover the surgery, then hysterectomy becomes a reasonable choice according to providers. However, this is neither patient centered care nor evidence-based medicine. The experiences of and standards of care for transgender men compared to the standards of care for cisgender women for hysterectomy show that evidence based medicine and patient centered care cannot explain the different decision processes for these patient groups. In the case of trans men, hysterectomy becomes an acceptable risk because trans men are men and this surgery supposedly brings the body into greater alignment with gender identity. However, the men I interviewed explained that these reproductive organs were inconsequential to their gender identities, thus conflicting with the assumption that these organs have a deeply gendered meaning. The acceptance of hysterectomy as a response to patient anxiety about pelvic exams and pap smears is understandable given expectations about what men's and women's bodies should be. The hysterectomy case suggests that removal of a healthy organ is shaped by ideas about men's bodies. The case of bilateral mastectomies and breast reconstruction for cisgender women show how these expectations play out for female bodies and why the removal of healthy body parts is medically justified in some cases but not in others.

### **Bilateral Mastectomy**

Prevailing medical wisdom indicates that the removal of healthy tissue is inappropriate because surveillance techniques are sufficient for managing cancer risk unless there is a significant statistical risk of disease over time. The heightened risk of breast cancer given a BRCA mutation has led to a gradual increase in acceptance of prophylactic mastectomy among

medical professionals. As a preventive measure, contralateral prophylactic mastectomies are far more contested and portrayed as a cause of concern by medical professionals than are bilateral prophylactic mastectomies, even though there may be an increased risk of developing a second cancer in the other breast for some people.

Risk management is at the core of protocols for treating BRCA positive patients and cisgender women with breast cancer. For women who are BRCA positive, health statistics have made prophylactic mastectomy a foregone conclusion. 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, ranging from 45% to 82% depending on the type of BRCA mutation and ethnic heritage (National Cancer Institute 2014, Chen and Giovanni 2007, Antoniou et al. 2003; King et al. 2003). In addition to BRCA there are a range of other genetic and medical conditions that increase a woman's risk for breast cancer and can influence her physician's surgical recommendations.

This statistical data is also important to patients in their decision-making process. No participant in this study who was diagnosed with a BRCA mutation reported that a physician tried to convince her not to have prophylactic mastectomies. Michelle articulated the predominant opinion of BRCA positive women in this study, "I kind of decided right then and there [when I was diagnosed] that I was going to have the mastectomy. ... I felt at that moment ... I could reduce a lot of risk and still have a good quality of life." This is also the prevailing medical perspective on treatment for a positive BRCA diagnosis. Quality of life encompasses the sense of normality that comes with avoiding increased screening, it indicates the avoidance of cancer, and encompasses the ability to appear socially as a normal woman who has not had

breast cancer. This is a point to which I return in the next section. When women diagnosed with breast cancer made similar associations between quality of life and risk mitigation, they indicate that their health care providers were not as agreeable as those of women who were BRCA positive.

Currently, biomedical research does not support the notion that surgery significantly impacts a woman's survival rate, unless she is at very high risk of developing cancer in her other breast. Instead, this research argues that increased surveillance is enough to mitigate risk of recurrence and that a desire for a bilateral mastectomy has more to do with an interest in the aesthetic outcome of breast reconstruction (Hawley et al. 2014; Jin 2013; Katz and Morrow 2013; Morrow et al. 2014; Rosenberg and Partridge 2014). However, increased surveillance is a hotly contested topic among medical professionals. Not only are the guidelines for screening frequency and timing debated, but so is the utility of these methods in actually preventing cancer (see 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. Participants in this study indicate that risk and quality of life have very different meanings for them than what were communicated by providers.

Women who chose contralateral mastectomies after breast cancer diagnoses believed that increased surveillance carried risks. Fran said, "I just wanted to get rid of the whole situation. I just don't want this worry all the time." Others expressed concerns about the risk of complication for other treatment plans. Linda was given the option to have a lumpectomy and radiation or a mastectomy. She was concerned about the effects of radiation and wary of a second cancer in her other breasts. Suzy was also concerned about radiation because in the event of a recurrence the

same area can't be radiated again. Suzy felt that a mastectomy was an almost inevitable outcome and that she might as well hedge her bets and remove both breasts.

Edie was told by her physician, "No, I won't [perform contralateral prophylactic mastectomy] because there's nothing wrong with the other one. It's healthy. ... I refuse to cut off a healthy body part." Breast cancer patients insist that their fears about recurrence, treatment side effects, or the emotional trauma of surveillance detract from their overall quality of life and that bilateral mastectomy is their best option to protect their peace of mind. The medical profession largely disagrees. Instead, for women with breast cancer the focus is on preserving a currently healthy body part, a consideration that apparently does not apply equally to transgender men or BRCA positive cisgender women. The surgical recommendations are not about healthy body parts, but about ensuring bodies match physical expectations for individuals with a given gender identity.

Increased surveillance is not the only risky practice about which women were concerned. They also explained that 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 considerable ambivalence about the most effective treatments. What women with breast cancer 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 in the other breast.

Current medical research tends to focus on the potential risks of a surgery that is not considered medically necessary. In their comprehensive review of clinical studies of patients



who had unilateral mastectomies compared to patients who had prophylactic bilateral mastectomies, Osman et al. (2013) indicate that women who have bilateral mastectomies have higher complication rates than women who have unilateral mastectomies. However, these complication rates remain low without reconstruction (7.6%) while higher rates of complications (64%) are associated with immediate reconstruction. If a cis woman desires to live flat, the complication rate is insufficient evidence to avoid surgery.

The path to a mastectomy is fairly straightforward for a cisgender women with a BRCA mutation. The medical community generally accepts that this surgery fits into the preventive health care model and can lead to a significant reduction in breast cancer risk. While surveillance is an option for both BRCA positive women and those with breast cancer, it is the only medically justifiable option for women with breast cancer, even though they are at increased risk (compared to the general population) for contralateral cancer.

Medical risk is a critical consideration in decisions about elective surgeries to prophylactically remove a body part. For trans men and BRCA positive cis women, this removal is warranted, yet for cis women with breast cancer it isn't. Bilateral mastectomies for cis women are implicitly understood as the removal of a body part essential to an identity as a woman. In the case of BRCA positive women this is justifiable because the cancer risk is so great. Additionally, once removed, breasts can be surgically reconstructed to help restore that identity.

Women who choose to remove their breasts without supporting medical evidence challenge the common sense belief that women must have breasts. This reliance on evidence discounts the few qualitative studies published in medical journals that find that women who choose contralateral mastectomies after a breast cancer diagnosis are happy with their decisions and would make the same decision again. This data and the claims of patients are not always trusted

by physicians. The women I interviewed who chose bilateral mastectomies after breast cancer diagnoses were often doubly confounding for physicians as they not only wanted to remove their breasts against the findings of biomedical research, but the majority also did not want to pursue breast reconstruction.

### **Breast Reconstruction**

Following mastectomy, many women decide against breast reconstruction. The percentage of women who do not obtain breast reconstruction ranges from 41.6% (Morrow et al. 2014) to 83.5% (Alderman et al. 2006). Medical professionals are particularly concerned with these statistics because breast reconstruction is viewed as a critical component of positive psychological recovery due to purported positive impacts in helping patients cope with a loss of femininity, mood disturbances, as well as interpersonal, sexual, and marital dysfunction that can follow from mastectomies (see for example, Dean, Chetty, and Forrest 1983; Nahabedian 2015; Parker 2004; Rabinowitz 2013; Stavrou et al. 2009). In one prominent study, medical researchers found that “Both immediate and delayed breast reconstructions provide substantial psycho-social benefits for mastectomy patients” and offer “the most effective means for restoring psychological wellbeing after a mastectomy” (Wilkins et al. 2000).

In his commentary on this research, Dr. Bruce Cunningham directly addressed these cultural beliefs: “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 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."

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. Unlike similar studies, Rowland et al. compared women who had reconstructive surgery with those who did not. Data from one group of patients alone simply indicates that those who had the surgery were content with their choice, not that making a different choice necessarily leads to a more negative outcome. Nor does it account for the many factors that can influence the impact of this decision on interpersonal, sexual or marital dysfunction. The strength of ideologies of gender and sexuality are so great that studies that run counter to common sense assumptions have little impact.

The medical framing of breast reconstruction assumes that patients will have breast reconstruction if offered the option and provided with examples of how successful the surgery can be. Patients are given not only with formal information about reconstructive options, but physicians also told those I interviewed that reconstruction is "the fun part" of breast cancer. Katie's doctor told her, "You get a mastectomy, you get new breasts, and you get a tummy tuck. Which, post-children sounded like a great idea to me."

Many women find great pleasure in being breasted and breast reconstruction can be central to restoring a sense of self after the physical and emotional difficulties of breast cancer. However the reality of reconstruction fails to convince some women. Many of the women I interviewed turned to the internet to search for images of both reconstructed breasts and flat, post-cancer, chests. After seeing these images and understanding the specifics of breast

reconstruction, several women expressed sentiments similar to but not always as colorful as Edie, whose response to reconstructive surgery was "Not on my fucking life." The women I interviewed were not satisfied by reconstructive surgery and often characterized reconstructed breasts as "frankenboobies." They typically viewed flat chests as more aesthetically appealing. Other women, like Sandy, were fiercely protective of their muscle function. All the women in this study who live flat were very clear that this was a personal choice. Reconstruction was not right for them, even though it may be a great option for someone else.

Despite their informed intent to live flat, the women I interviewed reported that physicians made great efforts to convince them to have surgery. Fran had to watch a video extolling the benefits of reconstruction before making her final decisions. She found the video offensive and told me, "it was infuriating to me after having made the decision [to live flat] 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."

The notion that women will be unhappy following mastectomy unless they get reconstruction was taken to an extreme in the case of Catherine, who had to undergo expensive psychological testing when she told her doctor that she wanted to live flat. "My doctors were kind of floored that I would want to spend the rest of my life without reconstruction ... It was a constant questioning of my mental state and my decision-making process." She was required to undergo psychological screenings not covered by her insurance. 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. At the time of her mastectomy, Catherine didn't feel like she had the option to find a different provider who might be more accepting of her desired embodiment so she acquiesced to therapy. This is not

surprising given that decisions about reconstruction are made in conjunction with managing the emotional upheaval that comes with a cancer diagnosis. The possibility of finding a different physician or medical team hadn't occurred to Catherine during her initial treatment. Although Catherine is the only participant who recounted this requirement for therapy, the experience of not feeling like there is a choice of provider once care has begun is striking. Many participants described their efforts to find the best care possible after being diagnosed. This creates a dilemma when the best care for treatment may not be open to the way a patient hopes to live after cancer.

In other cases, there was no discussion between patient and provider. Some women assumed that a flat chest was the default result of a mastectomy. Suzy explained, " I never mentioned it to [the surgeon], 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. ... 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." Despite her desire to live flat, Linda's surgeon left skin she described as "sharp points ... like shirt collars. They had substance to them, like cartilage." For both Linda and Suzy, their surgeons assumed that they would eventually want breast reconstruction and purposefully left extra skin to accommodate implants, even though neither woman expressed this interest to her physician.

Living flat is rarely an option presented to women. A pamphlet provided to cisgender women at one prominent cancer treatment facility answers a series of questions a patient may have as she considers breast reconstruction, including "do I have to have breast reconstruction?" Although the answer in the pamphlet is "no," the paragraph response mostly concerns breast

prostheses and ends with these two sentences, "Living a long cancer-free life is our goal. Keeping your femininity is just as important, too" (Crosby ND).

For some, breasts are integral to their identities as feminine women, yet participants who live flat challenged the association of breasts with femininity. After her contralateral mastectomy without reconstruction, Samantha stated, "I feel more feminine than I've ever felt." In this respect, a sense of embodied femininity can be important both for those who choose reconstruction and those who live flat. Samantha and other women like her are highlighting the taken for granted connection between breasts and femininity and suggest that femininity can be embodied in other ways.

The risk narrative also plays into some women's decisions about reconstruction. Concern about post-surgical complications was an important factor in some women's decisions to avoid reconstruction or to reverse the surgery after it had been done. Depending on the type of reconstruction and individual health factors, reconstructive surgeries can have a complication rate of up to 46.4% (See Jagsi et al. 2014; Brooke, Mesa, and Uluer 2012; Sullivan et al. 2008). Alison explained that "the things [the surgeon] 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." Kate developed a serious infection in her implant and ultimately decided to have the surgery reversed. Despite very real risks of complication and poor evidence suggesting a strong correlation between surgery and positive experiences in recovery, reconstruction is an elective surgery that many physicians strongly recommend.

Breast reconstruction is not an option routinely presented to men with breast cancer. Due to having less breast tissue than the average cisgender woman, men diagnosed with breast cancer

typically only have mastectomy as a surgical treatment option. Frank paraphrased his surgeon's opinion, stating, "You're a guy. It's a rather simple decision." Many men in this study reiterated that a mastectomy is an easier decision for men than for women. Ezra explained that "going through a single or double mastectomy affects [women] a lot more psychologically because it is so wrapped up with your image as a feminine person. For guys it's just an inconvenience... it's not that bad." In describing the mastectomy and recovery, Frank's surgeon told him, "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." In other words, there was no additional discussion of breast reconstruction for men as there would be for women.

Larry lamented the fact that breast reconstruction was not offered to him. He was told by his physician that reconstruction was available but that men generally don't do it. Tim was the only cisgender man I interviewed who explicitly asked his medical team about reconstruction. After meeting with a plastic surgeon he decided, that the options of tattoos or nipple reconstruction were "weird." The lack of choice about reconstruction is significant, given the concerns men shared in this study regarding their post-mastectomy bodies. Frank felt "deformed." Ed expressed his desire not to "cause people any queasiness." Ed described having a concave chest after surgery and explained that he would have appreciated being offered something to fill the space.

Reconstruction is framed as necessary for healing, but only for women. This is not based on actual medical evidence, nor is it truly based on a concern for patient-centered care. Women who wanted to live flat were pressured to have reconstruction. Cisgender men were not offered reconstruction or felt ashamed for asking providers about it. This inconsistency highlights

normative expectations about gendered bodies. Recovery from breast cancer is only complete when these expectations are restored or preserved.

### **Conclusion**

The surgeries discussed in this paper indicate the importance of gender ideologies to the ways surgeries for “female” cancers are presented to and understood by patients. The accounts of elective surgery described in this paper suggest that these decisions for gynecological and breast cancers are not primarily about medical evidence or patient-centered care. Instead, these cases suggest that a patient’s ability to easily access elective surgical care is determined, at least in part, by assumptions about appropriately gendered embodiment rather than through a consideration of biomedical evidence or patient desires. Further, these findings clarify that there is not a universal association between gender identity and desired embodiment. Rather, there are a variety of ways that individuals desire to embody their gender. Despite allegiance to patient-centered medicine, providers may struggle to accommodate patient desires that run counter to expected norms about gendered bodies, particularly when there is a lack of clear evidence to guide medical advice.

Only those who shape their bodies through surgical means in accordance with gender norms get easy support from the medical establishment. The experiences of participants in this study indicate that patients experience differential reactions to their interest in or suitability for these elective surgeries. These differences are best explained through an understanding of taken for granted assumptions about men, women, and their respective bodies. These beliefs may influence the care patients receive, the degree of trust they have in their providers, and reproduce ideologies of gender. This research shows how medical interactions are critical in the process of legitimating normative ideas about gendered bodies. If the gender problem in medicine is to be



solved, medical professionals and social researchers need to collaborate to better understand the ways cultural ideologies shape clinical practice and in turn, reproduce these ideologies.

Additionally, medical professionals need to rethink the central tenets of patient-centered care in order to allow for the multiple desires that patients have for their bodies.

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