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## Going Flat: Challenging Gender, Stigma, and Cure through Lesbian Breast Cancer Experience

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Going Flat: Challenging Gender, Stigma, and Cure through Lesbian Breast Cancer Experience

by

Beth Gaines

A thesis submitted in partial fulfilment  
of the requirements for the degree of  
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## **ABSTRACT**

This paper explores the decision-making process of reconstruction surgery among lesbian breast cancer patients to better understand how identity impacts healthcare decisions. Breast cancer patients experience the disease in unique ways due to gender, sexuality, race, and class, impacting their individual decisions regarding treatment plans. Many breast cancer patients face mastectomy surgery as the first plan of treatment after diagnosis. By exploring the impact of gender, sexuality, stigma, and ideas of cure, this research aims to advance research about breast cancer by recognizing why some lesbian breast cancer patients forego reconstruction surgery and instead choose to “go flat.

## **CHAPTER ONE:**

### **INTRODUCTION**

One in eight women will be diagnosed with breast cancer in their lifetime (*U.S. Breast Cancer Statistics*, 2021). While this statistic is alarming because of the sheer number of cases it represents, there is still quite a bit that we do not know about those affected by the disease. Breast cancer patients experience the disease in unique ways due to gender, sexuality, race, and class, impacting their individual decisions regarding treatment plans. Pressures to align one's health care plans with heteronormative ideals of femininity can influence such decisions. One such decision is that of breast reconstruction surgery. According to the American Society of Plastic Surgeons, breast reconstruction is up 75% over the last twenty years (2020, p. 10). Research suggests there are several reasons for such a significant increase. These reasons include the advancement of mastectomy/reconstruction techniques, decreased operative hours, and shortened post-operative recovery, as well as the Women's Health & Cancer Rights Act of 1998, which requires insurance companies to cover reconstruction surgery (Panchal & Matros, 2017, p. 3). Additional reasoning for the rise in reconstruction surgery must consider the gender "norms" that our society holds to be true. These norms have been "routed into a white, normative, heterogendered ableist subjectivity" (Brandzel, 2016, p. 129). This pressure can be overwhelming when women may face "a dizzying array of gender challenges and experiments [that] come with the initiations of surgery, of chemotherapy, of hormone therapy" (Sedgwick, 1992, p. 204). However, not all women will succumb to the pressures to return to the "ideal woman's body" after mastectomy by reconstructing their missing breasts. Instead, some women are choosing to forego such cosmetic surgery by

deciding to “go flat.” This paper will focus on sexual and gender minority (SGM) women who undergo mastectomies and opt out of reconstruction surgery.

As a breast cancer survivor who identifies as a cisgender lesbian woman, I am keenly aware of how gender and sexuality impact health decisions. Having to decide between reconstruction or choosing to “go flat” after my bilateral mastectomy forced me to consider both my gender and sexuality in ways I had not before. The decision to forego reconstruction was a personal decision, yet was impacted by heteronormative notions of femininity, as well as the interpersonal relationship with my health care providers. I found there to be minimal support available for sexual and gender minority (SGM) women going through breast cancer. Much of the literature reinforced the promotion of a hyperfeminized woman as the ideal cancer survivor. There is also a significant gap in the literature on SGM women and breast cancer. While “feminist scholars have revealed the heteronormative assumptions embedded in the clinical and social management of breast cancer...little attention has been given to lesbian and bisexual women’s experience of mastectomy and decisions about breast reconstruction” (Rubin & Tanenbaum, 2011, p. 402). I hope this research provides answers to some of the questions that have been left unasked.

SGM women include those who identify other than heterosexual, as well as those who live beyond the gender binary in ways that do not conform to societal ideals of femininity. Because an individual’s gender and sexual identity intersect, it is essential to investigate SGM women and their experiences with breast cancer so that we may better understand their health decisions. While all SGM women who go through breast cancer need more study, this research will begin that process by focusing on people who identify as lesbians. I will be asking the following research questions: How do gender and sexual identity impact the treatment decisions of breast cancer patients who undergo mastectomies? How does the decision to “go flat” then impact breast cancer

patients' gender and sexual identities? In other words, is there a correlation between one's identities and decisions to "go flat"?

I will begin this thesis by identifying the various breast cancer treatments women face. Then, I will explore current research that focuses on heteronormative ideas of femininity within our society that may influence a woman's health decisions and address how health care providers play a role in influencing healthcare decisions. Finally, based on 16 interviews that I conducted with individuals who identify as lesbian breast cancer patients, I will examine how gender and sexuality impact women's decisions about reconstruction surgery. This paper hopes to shed light on how women negotiate ideas of femininity within the SGM identity while deciding to "go flat."



## **CHAPTER TWO: LITERATURE REVIEW**

### **Reconstruction vs. Going Flat**

Upon diagnosis, breast cancer patients are immediately faced with having to make difficult decisions about their bodies that will have both physical and emotional impacts on their lives. Depending on the invasiveness of the cancer, breast cancer treatments often consist of the “slash, burn, poison” regiment of mastectomy surgery, radiation, and chemotherapy. Surgeries to remove the cancer include lumpectomy (the removal of the area of the breast affected by the cancer) or a unilateral or bilateral mastectomy (the removal of one or both breasts). Decisions about surgery also include whether or not to have reconstruction surgery. Reconstruction “refers to rebuilding a breast that was removed in response to cancer diagnosis and it may or may not include the use of an implant” (Sischo & Martin, 2015, p. 79). Those who forego reconstruction, or “go flat,” opt out of additional surgeries intended to restore a “normal” female appearance. This decision is usually made immediately after diagnosis, and surgery is scheduled within weeks, placing enormous pressure on women during an already stressful time. Such decisions often require an individual to negotiate several aspects of their identity, including gender and sexuality.

A recent study by Baker et al. (2021) found that 73% of the 931 breast cancer patients who underwent mastectomies listed mastectomy alone as their first choice for surgery. The leading reasons behind choosing to forego reconstruction included “avoidance of a foreign [object in their] body (39.9%) ... lower complication rate (34.9%)” (p. 2496). About half (51.1%) reported that “they did not think their breasts were important for body image” (p. 2496). While this study

suggests a significant percentage of women may prefer to forgo reconstruction for various reasons, the authors note that about 20% of the respondents “felt that their surgeon did not support their decision” to do so (p. 2500).

In a similar study, conducted in Australia, authors Héquet et al. (2013) found that of 1937 patients surveyed, “1315 (67.9%) had no surgical reconstruction” (p. 3). A significant number (80%) mentioned that the choice to forego reconstruction was a “personal choice” and that concerns about further surgeries and additional recovery time influenced their decisions (p.8). While Héquet et al. do not focus on patient-provider interactions specifically, they do look at the dissemination of information regarding reconstruction that patients receive. They found that 41% of respondents found the information provided to them “entirely unsatisfactory” (p.7). This is important to note because while these surgical decisions must be made in a timely manner, patients often depend on their providers for knowing their treatment options. When appropriate education about surgical options is not provided, breast cancer patients risk the possibility of making an uninformed decision and depending on the surgeon to perform what they feel is appropriate for the patient. This becomes dangerous as the surgeon may hold various biases about gender and sexuality that influence their surgical methods.

### **Femininity and Flat Denial**

Breasts are often the “defining features of the female body and the basis upon which women’s bodies are judged” (Sischo & Martin, 2015, p. 77). Through the heteronormative lens of the male gaze, women’s bodies have been the sight of sexual objectification. Women have been “programmed to view our bodies only in terms of how they look and feel to others, rather than how they feel to ourselves and how we wish to use them” (Lorde, 1997, p. 57). This ideology that a woman’s worth is connected to her body suggests that she must keep up feminine appearances

in order to have value. In other words, for women to perform gender in the “normal” way, they must embody femininity as constructed by society. Audre Lorde, a lesbian poet, argues that “the emphasis on the cosmetic after surgery reinforces this society’s stereotype of women, that we are only what we look or appear, so this is the only aspect of our existence we need to address” (Lorde, 1997, p. 50). In a society that places so much emphasis on the physical appearance of women, it is no surprise that women often conform to such stereotypes of femininity.

Ideas of femininity present themselves throughout our culture, perhaps nowhere as deeply as within the cause-related marketing of breast cancer awareness campaigns. This pink ribbon culture has only reinforced these problematic assumptions of femininity by “normalizing women’s experience through appearance and manner contributed to a model of survivorship that aligned both the medical consumer model and traditional femininity” (Sulik, 2011, p. 36). Such marketing is often used to showcase what it means to be a breast cancer survivor (read: white, middle-class, heterosexual woman). These women are “expected to be optimistic and strong yet attempt to restore their bodies to traditional femininity through wigs, makeup, prostheses, and breast reconstruction” (La et al., 2019, p. 2). Jain (2007) echoes this sentiment when she states that “women are still directed toward disguise through makeup, wigs, and prostheses rather than toward politics” (p. 508). Instead of focusing on preventing a disease such as breast cancer, cause-related marketing often places the emphasis on how to survive it by looking and behaving in certain ways. These images also overwhelmingly exclude racial minorities, such as Black women, who are just as susceptible to breast cancer as their white counterparts. According to the American Cancer Society, it is estimated that over 36,000 Black women will be diagnosed with Breast cancer in 2022 (n.d., p. 4). This number is important because it represents approximately 13% of all women diagnosed with breast cancer nationwide. Also important, is that 13% of breast reconstruction

surgeries in 2020 were performed on Black women (“2020 Plastic Surgery Statistics Report,” 2020, p. 25). Therefore, we must consider not only gender and sexuality but also how race and class impact ideas of femininity and access to procedures such as reconstruction surgery. Notions of femininity are deeply connected to the patriarchal, heteronormative status quo of what it means to be a woman in our society.

Hegemonic ideas of gender also play a significant role in how health care providers understand treatment options for women. Because breast (and gynecologic) cancers are “biomedically and culturally coded as ‘women’s cancers’” SGM patients feel that their access to “culturally and competent care” is impeded (Bryson et al., 2018, p. 348). Such understandings of medical professionals are based 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 experience” (Sledge, 2019, p. 2). Such problematic ideas of who deserves care have led to what is called “flat denial,” which is when “surgeons advise against or do not offer the option of no reconstruction after mastectomy or leave excess tissue to facilitate future reconstruction against the patient’s wishes” (Baker et al., 2021, p. 2494). In one study of 931 participants who opted to “go flat,” 22.2% “experienced a high level of flat denial” (Baker et al., 2021, p. 2496). Rubin and Tanenbaum (2011) reported a similar finding in their research, stating that most participants of their study “faced considerable pressure, both implicitly and explicitly, to have reconstruction.” They report that “physicians framed breast reconstruction as a ‘natural’ step in treatment following mastectomy” (p. 406). Medical professionals are not exempt from holding biases that may impact the care they provide patients. Such biases may be influenced by homophobia, sexism, racism, etc. In fact, “breast cancer patients are constantly detoured away from inevitable intersection connections to transgender embodiments, queered affects, disabled

communities, and the racialized, classed, and able-bodied operations of precarity” (Brandzel, 2016, p. 130). This further emphasizes the notion that reconstruction is the way to returning to what our society sees as the “normal” female body. La et al. (2019) suggest that because reconstruction surgery is often supported by such norms of femininity, choosing to “go flat” can disrupt these understandings. Therefore, when women consider forgoing reconstruction, they “may be marked as oppositional, as making a political statement with their bodies” (Rubin & Tanenbaum, 2011, p. 407).

### **SGM Women Going Flat**

How, then, do we understand the experience of SGM women who choose not to conform to heteronormative ideas of femininity and instead choose to “go flat?” When considering lesbian identities, gender representations can span the gender spectrum from “femme” (feminine) to “butch” (masculine), and everywhere in between. The gender expressions of lesbians can impact their reconstruction decisions because of the different ways that they identify with their breasts. For example, a femme lesbian may dress in feminine clothing that forms to the shape of her breasted body. On the other hand, a butch femme may actually prefer to bind their breasts under their clothing because they would rather conceal them. These are just two examples, and I do not want to imply that lesbians are a dichotomy of femme or butch, rather I wish only to show that lesbians perform gender in many different ways.

In her memoir *Flat: Reclaiming My Body From Breast Cancer*, writer Catherine Guthrie tells her story of breast cancer through the lens of a cisgender, lesbian woman. She explains how her decision to forego reconstruction was difficult because “[her] breasts were a part of [her] queer-femme identity” (Guthrie, 2018, p. 162). She goes on to say that it was by “seeing [queer] people freely experiment with gender and sexual expression [that] gave [her] the room to explore

femininity on [her] terms” (p. 163). This further points to the intersection of gender and sexuality among breast cancer patients and how living within the queer community can allow for resistance to heteronormative cultural norms.

In their research, Bergeron and Senn investigate “the relationship between internalization of sociocultural norms and women’s attitudes toward their own bodies directly and through comparison of the body attitudes of lesbians and heterosexual women” (1998, p. 389). What they found was that lesbian and heterosexual women were “exposed to the same body ideal regardless of sexual orientation.” However, the groups “diverged on the degree to which they endorsed sociocultural norms” (p. 397). Their study also suggests that a feminist standpoint among both lesbians and heterosexual women impacts their internalization of gender norms (Bergeron and Senn, 1998). In other words, if we look at the intersection of gender and sexuality through a feminist lens, we can better understand why some SGM women are less likely to succumb to the pressures of femininity and choose to “go flat.” Brown and McElroy (2018) emphasize this point by stating that the “choices SGM [breast cancer] patients make about breast reconstruction are personal, although internal and external forces can politicize these choices” (p. 404). The idea here is that “because lesbian women have immersed themselves in a culture that places less emphasis and importance on the heteronormative standards, they are somewhat protected from experiencing BID [body image disturbance] to the same degree as heterosexual women” (Dahlenburg et al., 2020, p. 137).

SGM women may face the additional challenge of having to decide whether or not to “come out” to their health care providers. A significant element of “cancer care for sexual and/or gender minority patients is a perception of an intrusive level of risk linked with disclosures of sexual and/or gender minority identity in cancer care environments” (Bryson et al., 2018, p. 346).

Many SGM patients may face minority stress and social stigma attached to their identities when interacting with health care providers. SGM women may find it difficult to discuss their gender or sexual identities with their doctors for fear that their provider may not support their identity and therefore not understand or support the patient's decisions to "go flat." It is important to note that "even when providers do not enact outright discrimination or hostility, the marginalization of sexual minority identities in patient-provider sexual health communication reinforces invisibility and continued stigmatization of these identities" (McKenna et al., 2020, p. 614). The added stress of navigating the reactions of health care providers can place SGM women in a difficult position to choose between society's pressure to conform to the idealized feminine body or their own health and happiness.

## **CHAPTER THREE: THEORETICAL FRAMEWORK**

The three major theoretical frameworks that I have chosen to use in my research are gender as performative, stigma and narratives of cure, and intersectionality theory. Each of these theories offer important contributions to the understanding and analysis of the research being developed. Gender theory will be used to recognize and understand how gender is performative and not simply an innate characteristic of one's self. This is important because of the ways that reconstruction surgery deals with a very gendered aspect of the female body, her breasts. Recognizing stigma and narratives of cure will be used as a way to understand how embodiment is impacted by social and cultural structures that suggest what a "normal" body looks like. Because I will be looking at the amputation of the breasts of cancer patients, it is important to understand what a flat chest means as individuals who forego reconstruction navigate the world in their "new" body. Recognizing and understanding the stigma that is attached to "disfigured" bodies is vital to understanding the experiences of these individuals. I will also be looking at how the medical industrial complex suggests that a flat chest is something that needs to be "cured" by reconstruction surgery. And lastly, intersectionality theory is important as a way to fully understand how the intersecting identities of gender and sexuality impact the surgical decisions of lesbian breast cancer patients. My research aims to show that while the experiences of lesbian breast cancer patients may be similar in many ways, no two women will have the same lived experiences of health care. Never is reconstruction surgery only decided by one's gender and/or sexuality. Only by recognizing the



complexities among these women can we begin to understand the decisions they make about breast reconstruction surgery.

## **Gender as Performative**

The social construction of gender holds a contentious place within our society as both an arena that traditionally, within a patriarchal society, distinguishes between two genders (female and male) as static locations on a gender binary as well as a site of resistance against the status quo. It is true, that many individuals have no issue with accepting their place on the gender binary as either a female or male, their gender agreeing with the sex they were assigned at birth. However, we must also consider those who are not comfortable in either of those categories, perhaps landing somewhere along a spectrum of genders, or those who understand their gender as everchanging. Those individuals who go against the cisnormative ideology of gender risk being denied their identity, or erasure, within our society. The gender binary is dangerous as it assures us that “the very notion of ‘the person’ is called into question by the cultural emergence of those ‘incoherent’ or ‘discontinuous’ gendered beings who appear to be persons but who fail to conform to the gendered norms of cultural intelligibility by which persons are defined” (Butler, 2006, p. 23). In a world that categorizes individuals as a form of surveillance, gender has historically been one location that reinforces not only patriarchal notions that men are superior to women, but that those who do not identify as either simply do not exist at all.

Gender theorist, Judith Butler, challenges us to think about gender as not simply an either/or identity, but that of the ways in which gender identities of individuals are “performative.” Butler suggests that gender is not stable, but rather, constantly informed by one’s performance of self as “instituted in an exterior space through a *stylized repetition of acts*”(2006, p. 191). As women undergo breast cancer treatments, their physical bodies change in ways that challenge the

status quo of what our society understands as feminine, and in turn, influences how one may perform gender. Therefore, it is important to recognize and understand how breast cancer patients understand their gender identity before, during, and after treatments such as mastectomy surgery. How do breast cancer patients understand and perform their gendered selves? Does the gender binary get disrupted for patients who previously identified as cisgender? How does gender get managed through treatment decisions such as mastectomy surgeries?

### **Stigma and Narratives of Cure**

The next area of theory that is of importance in this research is that of stigma and narratives of cure. Sociologist Erving Goffman (1974) argues that through society's categorization of individuals, there rests the dichotomy of those who are seen as "normal" and those who are seen as "others." For example, people who possess "abominations of the body" are considered to hold a stigma because of an "undesired differentness" that suggests the individual is "not quite human" (Goffman, 1974, p. 5). Because breast cancer treatments have the ability to alter one's body by amputation of the breasts it becomes clear that under Goffman's understanding of stigma, mastectomies can be seen as a physical abnormality. This is emphasized through the normative ideas of what a woman's body should look like, complete with breasts. If a woman is faced with mastectomy surgery, she must decide how to approach the stigma that will be attached to having a flat chest. She is left with the task of "managing information about [her] failing" through reconstruction, use of prosthetics, or none of the above. Goffman emphasizes this point by stating that one must consider, "to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where" (1974, p. 42). This choreography of performing one's identity can also be impacted by their sexuality. Goffman considers homosexuality to be deviant and therefore a stigma that lesbians will hold. This

compounded “otherness” that lesbians with breast cancer face is likely to influence treatment decisions regarding reconstruction. Both the altered body in the case of breast cancer and homosexuality, present the opportunity to “pass” within our society by conforming to standards of femininity. In fact, Goffman argues that “because of the great rewards of being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent” (1974, p. 74). This point is further emphasized by Bryson et al. (2018) who state that the “changes to gendered embodiment made sexual minority cisgender breast and/or gynecologic cancer patients acutely aware of the ways in which their access to public space, knowledge, or mobility was affected by these bodily changes” (p. 354). Therefore, understanding how the threat of stigma influences the breast cancer treatments of lesbian women becomes an important location of study.

Having stigmatized conditions suggest that one “needs” a cure to get rid of the stigma. By understanding stigma and narratives of cure, we are introduced to the idea of “cure” and what it means to “fix” that which is considered “broken.” Eli Clare (2017) draws our attention to this idea of *restoration* in their beautifully articulated work, *Brilliant Imperfection*. Clare argues that the ideology of cure requires “damage, locating the harm entirely within individual human body-minds ... grounds itself in an original state of being, relying on a belief that what existed before is superior to what exists currently ... [and] seeks to return what is damaged to that former state of being” (2017, p. 15). The medical industrial complex relies on this ideology by “ensuring that body-mind trouble no longer exists” by suggesting that bodies that have been changed through illnesses such as breast cancer need to be restored to their previous state in order to be “whole” again (Clare, 2017, p. 76). It is important to point out how such politics of cure are a “tool of patriarchy, enforcing sexist and racist standards of beauty” that created the ideal human as a white, cisgender, heterosexual, male. While the possibility of even achieving such a status is near impossible for the

majority of people, it would be absurd to assume that it is even the goal of most. Therefore, recognizing stigma and narratives of cure offers the opportunity for resistance to ideologies of cure that present assumptions of one's identity by allowing those who are considered to have "broken" body-minds to instead claim self-love and a sense of pride. This is important to consider, particularly in the experiences of breast cancer patients who are faced with surgeries that disrupt their body-minds. We must also consider that the medical industrial complex, and physicians, in particular, offer and often encourage reconstruction surgery as the way to return a woman's body to its previous state, to be "whole" again. And lastly, it cannot be lost on us to recognize the danger of how cure is represented in the enormous realm of cause-related marketing geared towards breast cancer. The endless races and walks along with the pink ribbons placed on almost every item available for sale, all in the name of cure. The hyperfemininity on display in such marketing promotes images of white, middle-class, happy, and healthy-appearing women, with breasts. These images suggest that the goal of cure is not only through cancer research but also through the reconstruction of embodied femininity. Also, while these fundraisers promote the idea of raising money for research and cure, they are ignoring the need for the "broad-based access to medical care, housing, education, and employment" that many breast cancer patients need (Clare, 2017, p. 88). By spending so much money focusing on the future of breast cancer, these charity organizations are failing to recognize the social injustices that people with diseases like breast cancer face.

### **Intersectionality Theory**

The last theory that this research requires is that of intersectionality. Coined by legal scholar, Kimberlé Crenshaw, intersectionality is a framework that considers the multiple identities that one holds to better understand how societal oppressions are compounded in their lived

experiences (Cho et al., 2013). Intersectionality is of vital importance to my research because no two individuals will experience breast cancer the same way. Each person carries complex identity formations that consist of gender, sexuality, dis/ability, race, class, etc. While considering the experiences of a particular community, in this case, lesbian breast cancer patients, it is crucial to recognize that intragroup experiences differ in ways that present endless variations of experiences. For example, a poor woman of color may face the decision of reconstruction surgery differently than a white woman because of socioeconomic constraints or racial discrimination that limit access to such treatments. Not only may she not have the ability to miss work to have the surgery, but she may also not have transportation, or a support system in place to help with recovery. She may also face medical racism before, during, and after her breast cancer due to biases that healthcare workers may hold. The multiple oppressions that one holds and the perceived stigma that an individual faces only makes decisions about, or even access to, surgeries such as reconstruction that much more difficult.

## **CHAPTER FOUR:**

### **METHODOLOGY**

#### **Semi-structured Interviews**

The methodology used in this research was semi-structured interviews that were conducted, online, with lesbian-identified breast cancer patients. I chose interviews as my research method because the group of individuals that I spoke with have historically been left out of research due to their particular identities. Most medical research does not account for sexuality among the demographic information that is collected. Therefore, we are limited in what we know about lesbians and breast cancer. Bryson et al. (2018) argue that “whereas quantitative evidence of cancer-related health disparities indicates the sheer existence of inequalities, there is urgent need for explanatory, qualitative accounts of experiences and attention to narratives of cancer health and care decision-making linked with these inequalities” (p. 343). By interviewing lesbian breast cancer patients, I was able to bring the voices of this marginalized group into the discussion of healthcare experiences. The goal of the research is to recognize the particular needs and desires of lesbian breast cancer patients as they navigate their diagnosis, treatment, and recovery. Interviews provide a format that allows their story to be told in their own words. This creates an opportunity for assumptions about gender, sexuality, stigma, and cure to be laid to rest.

To gain access to interview subjects for my research, I first created a flyer (see Appendix A) that acted as a call for research subjects to participate in my study. This flyer was disseminated to LGBTQ+ groups connected to Moffitt Cancer Center in Tampa, Florida as well as displayed in their breast cancer clinic. I also shared the flyer on social media, including Twitter and Facebook.

Sharing on social media platforms allowed me to reach a group of participants beyond the Tampa Bay area. The individuals who participated in the interviews were located across the United States as well as in Canada and the UK. They ranged in age from their mid-twenties to mid-seventies. The interviews each lasted approximately 45 minutes which allowed the participants to share their stories and for me to ask specific questions about the impact of gender and sexuality on their surgical decisions.

I began each interview by asking the participant to start off by telling me about their experience with breast cancer, beginning with their diagnosis. As participants told me their stories, I asked them to speak on specific areas which were framed by a list of questions (see Appendix B) that I had prepared to guide the interview. I then completed a qualitative analysis of the interviews by coding the transcripts of each interview. The coding allowed me to focus on common themes that suggested significance within the interviews. These themes included surgical decisions, gender, sexuality, and patient-provider interactions. These common themes also allowed me to relate the meaningful responses to the theoretical framework I have listed above. I was then able to interpret responses that relate to understandings of one's gender and sexuality as well as ideas of stigma and cure.

The participants in this research included women who self-identified as lesbian breast cancer patients. Additional demographics were not asked for directly, however, some participants did provide their age, ethnicity, and geographical location. The women in my studied ranged in age from their mid-20s to mid-70s. Of the 16 women interviewed, three identified as non-white (1 Asian-American, 1 Lebanese-American, and 1 Turkish-American). Participants were located across the United States (14), and in Canada (1) and the United Kingdom (1).

All interviews were video/audio recorded online and then transcribed to text. The

recordings and transcriptions were then saved to a secure file on my personal computer. I am the only person with access to this file. I will save this file only as long as I need access to it for research purposes. This may include research to be conducted for a dissertation. Once access to the file is no longer needed it will be destroyed. To further secure the privacy of the individuals who participated in this research, I have replaced their names with pseudonyms. This prevents anyone from reading the paper to be able to identify the individuals and their statements.

### **Limitations**

The limitations of this study include the small sample size of participants. We cannot assume that the interviews of twenty individuals can speak for the masses. And while this study was able to include participants from different geographical locations, the study does not analyze other demographics, such as race and class. Medical racism is alive and well in our healthcare system and women of color, particularly Black and Latinx women, may be deterred from volunteering to participate in a study, regardless of the intentions of the study. The other limitation to consider is the amount of disclosure the participants provided about their experiences due to their sexuality. We live in a world that leads many non-heterosexual individuals to conceal such information, particularly from a stranger. And while each participant self-identified as a lesbian, there is still the chance that their stories may have been told with some discretion.



## **CHAPTER FIVE:**

### **FINDINGS**

Breast cancer is a complex disease that brings with it the unique lived experiences of women around the world. The surgical decisions that breast cancer patients make are often influenced by the identities that they hold. Some women bring with them a family history of breast cancer or a genetic disposition to the disease. And for some women, breast cancer comes without any cause or warning. Our lived experiences also impact our ideas about gender and sexuality and how those pieces of our identities then impact surgical decisions such as mastectomies. For this research study, I was able to interview 16 lesbian-identified breast cancer patients. And while these women represented various ethnicities, including Asian-American, Turkish-American, and Lebanese-American, ethnicity was not mentioned as significant to their surgical decisions. All of the participants in this study elected to have either a single or bilateral mastectomy without reconstruction.

For many of these women, the decision to have mastectomy surgery came down to health reasons, first and foremost. For them, it was their way of reducing the risks of breast cancer recurrence. The decision to reconstruct or not varied among participants from avoiding additional surgeries to ideas about body image. After interviewing these women, it has become clear that both gender and sexuality are important pieces of the decision-making process that is required of them. Some women identified with their breasts as a part of their relationship with femininity while others had always seen their breasts as somewhat of a burden. Some women found being part of the LGBTQ+ community had nothing to do with their relationship with their breasts, while others

felt that because they were part of such a diverse community that it made altering their bodies less of an issue. What almost all of the women interviewed had in common was the frustration with how their medical providers (general and plastic surgeons) did not present “going flat” as a viable option after mastectomy. Additionally, there was not an acknowledgment of what is termed “aesthetic flat closure” when discussions of foregoing reconstruction did happen, suggesting a lack of language to explain what having a flat chest can look like. Aesthetic flat closure is when surgeons perform a single or bilateral mastectomy and close the surgical opening in a tight, clean way that does not leave extra skin. Surgeons will sometimes leave this extra skin as a way to make reconstruction surgery less complex. The problem lies in surgeons leaving this extra skin when the patient has stated that they do not want reconstruction surgery. This idea is known as “flat denial” among the breast cancer community. “Flat denial” and the disregard for “aesthetic flat closure” suggest that surgeons may be inclined to encourage reconstruction surgery as a means to “fix” what is “broken” while ignoring the equal importance of how the chest may look after surgery without reconstruction.

## **Gender**

The social construction of gender has led to the heteronormative idea of femininity and what a woman should physically look like. She is expected to have breasts and present in feminine styles of clothing and makeup to fulfill the status quo. However, breast cancer poses a threat to societal notions of the “ideal” woman when she faces the loss of one or both of her breasts. Individual women, however, understand their femininity in unique ways. Not all women embrace femininity in the same way. Some women understand femininity as a part of their physical presentation while others do not. Therefore, breasts are not always seen as necessary for a woman to feel feminine. This does not mean that breasts are not valued by those who do not relate them

to their femininity. Having a body part amputated due to cancer can be felt as a great loss to many women. At the same time, learning to navigate a world that holds such strong ideas of femininity can be difficult for these women. This may be the case when these women are, or fear being, misgendered in public due to the loss of one or both breasts.

The understanding of one's gender identity can vary greatly among lesbian women. Gender has the ability to impact how one sees the world, and how the world sees them. Breast cancer is a very feminized disease which suggests that the disease and gender should be understood the same for all women. However, as one individual that I interviewed stated, "There is a lot in the breast cancer field that is very pink and the idea of femininity and what it is to be a woman. So, you know, some of us will go up against that" (JC). JC is highlighting the fact that not all women will adhere to the heteronormative expectations of breast cancer patients, particularly of their surgical decisions. For individuals like JC, gender is not defined by traditional ideas of the "ideal woman."

The concept of gender as performative becomes clear in the variety of responses I received when I asked the participants if/how their gender impacted their decisions about reconstruction surgery. For some lesbians, their gender is understood as presenting socially in feminine ways (i.e. the ways in which one dresses, wears makeup, does her hair, and so on). For other lesbians, gender is more fluid and weighs less heavily on their understanding of self-identity.

For many of my participants, the physical appearance of one's body, that of having breasts or not, did not inform their ideas of femininity:

I've never really, you know, bought into the, you know, make-up, the clothes, the large breast thing. I was never focused on that part of my body. Of course, I love my body, I've just never really considered my breasts as part of my identity. (Iris)

Melissa echoed this statement when she mentioned, "I don't feel less feminine or more masculine.

I just never really identified with my breasts to begin with.” This idea of breasts not being a significant part of one’s identity is also shared by Jackie, when she said, “I don’t feel different about my gender and I think there’s a lot more to gender identity than the breasts.” For these women, breasts are a physical aspect of their biology, not a gendered aspect of their identity.

Even though the understanding of gender may vary greatly among lesbian women, and the (non)importance of their breasts as part of their identity, many participants stated that they still felt great loss after their mastectomy surgery. Skylar emphasized this point when she stated,

I feel like many female-identified humans, after many years of being put into a tiny little box of what bodies can and should look like, I finally came into a space where there was comfort in my 40s. I could be in my hips, I could be in my breasts, in my curves, and I felt very comfortable in that. ... I think the initial couple of months were super hard. Like, looking in the mirror was hard because I was previously this large-breasted person. I hadn’t thought about it before but they’re a part of who you are.

This feeling of loss was echoed by Iris when she stated,

I was never stereotypically super feminine before anyway. Of course, it sucks, you know, of course it does. But you know, I’m up and down emotionally about it. It doesn’t really have anything to do with femininity necessarily. It’s just loss, period.

Likewise, Nancy, who shared a similar sentiment about the difficulty of the decision,

But yet, when I made that decision I found it so difficult to make. I found it really interesting at the time making that decision how difficult I found it. For someone who wasn’t even that comfortable with her femininity.

Losing one’s breasts due to cancer can be a traumatic experience that comes with feelings of great loss, regardless of one’s gender or relationship with femininity. Nancy goes on to mention that

while she “dress[es] androgynously at best [and] would get misgendered on the streets even before this,” that it wasn’t until after her mastectomy without reconstruction that she got asked her pronouns in public for the first time.

Being misgendered proved to be a common concern of several of the research participants I spoke with. Marie mentioned, “I thought people were going to misgender me and I thought I was going to be really self-conscious.” Nancy also shared a similar concern, initially, when she said,

When I had my mastectomy, I was like, ‘What am I going to do when people misgender me?’ Looking back, I used to get misgendered before so in that sense, it was no different before or after ... I also worried about what people might say if they asked, ‘What happened to you? Where’s your breasts? Are you a man or a woman?’ I’ve landed with the idea that it’s ok to look like this and a majority of people may not be able to tell what it is, but it’s an honest mistake.

The fear of being misgendered shows that while these women are learning to understand their new bodies, they are also considering the reactions of others. For some, it is the gaze of others that can impact the feelings one has about her body more so than how she looks to herself.

What is clear, after speaking with these women, is that gender is a fluid concept and is very much a performative act experiences differently among individuals. The importance of breasts in relation to ideas of femininity varies greatly among these women. The feeling of loss can be felt by women when it comes to mastectomy surgery, regardless of their gender presentation. The worries of being misgendered, when felt, are often a result of being self-conscious about what others will think of a woman with a flat chest, and less about one’s own understanding of how gender can, in fact, look many ways.

## Sexuality

The impact of sexuality on reconstruction surgery decisions presents in two unique ways, one as a hindrance and the other as a possible benefit. First, the loss of breasts has been equated to a loss of sexual sensation for some women because breasts are an erogenous zone of the body. With the loss of one or both breasts, women can lose the sensitivity that can create sexual stimulation. Mastectomy surgery can impact the sexual relationships among lesbian couples in a negative way because of the stimulation that is lost with their breasts. For Samantha, the loss of her breasts for purposes of stimulation was, “the hardest thing, because they’re an integral part of intimacy.” She goes on to say,

I don’t know that healthcare providers or heterosexuals necessarily understand what breasts mean to some lesbians. I mean it’s more than just putting on a low-cut dress and going to dinner. It’s a very intimate part of lesbian relationships.

JC reiterated this point when she stated that she chose to do a single mastectomy instead of a bilateral mastectomy because she “wanted one breast for sex and for physical sensation.” Dana also contributed to this idea of lesbian intimacy and the loss of breasts in the decision-making process of choosing her providers, “I don’t really want to go to somebody that deals with heteronormative couples because they don’t understand ...we have two sets of boobs in our relationship.” Skylar also spoke to the lack of understanding that heterosexual providers may bring to the surgical decision-making conversations when she said,

There may have been an assumption that because I was already queer, [losing my breasts] didn’t matter as much, you know, as a straight woman. But for me, it did matter. And for another queer woman it might not matter as much. But I think there are still assumptions being made.

Friends and Family can further exacerbate the decision-making process, as Cara stated:

There was some assumption being made because I was a lesbian, because I'm in a same-sex relationship, that maybe breasts were not as important to me, because I wasn't looking to be attractive to a man. (Cara)

Barb echoed this point when she stated, "Just as I don't understand heterosexuality, they don't understand my homosexuality. They don't have the experience." Each of these women speaks to the importance of breasts within a lesbian relationship. Losing one or both breasts can be a hurdle to overcome when navigating intimacy post-mastectomy. This further impacts the surgical decision of women when heterosexual healthcare providers fail to recognize or acknowledge the needs of lesbian patients.

Not only is there a concern about the limit of understanding among heterosexual providers of the wants and needs of lesbian patients, but there was also a concern about the gender of providers. For many lesbian women, having a male provider touching their breasts was quite uncomfortable. Skylar speaks to this concern when she said of meeting her male surgeon for the first time:

He was a very kind man. But I haven't had a man touch my breast in 27 years. So I am on the exam table and his nurse is present, too. He's very calm, very kind, and he instructs me to 'calm down and relax' and I'm thinking 'you told me I have cancer and you're a man touching my body.' That's just a different comfort zone, you know?

As Skylar and Barb suggest, navigating the breast cancer experience can be difficult for many lesbian women because of misunderstandings and assumptions of providers that may occur. This can make the surgical decision that much more difficult for lesbians when being presented with options that might not align with their sexual identity. The gender of the breast cancer providers is

important to note as a male provider can lead to further discomfort for lesbian patients. For some, a male provider touching a woman's breasts can be triggering of past traumas.

While sexual identity often made patient-provider interactions difficult for some lesbian women, some found their sexual identity to be the piece that made their decision-making process a little easier. The LGBTQ+ community is quite diverse as it embraces the identities of many sexualities and genders. Therefore, many of the participants I interviewed mentioned that because they were a part of this diverse group, the pressure to align with heteronormativity had less of an impact on their reconstruction decisions. This is because for many of these women, "fitting in" to the heteronormative ideals of femininity was not something they did before breast cancer. Nancy highlights this point when she stated:

Everybody thinks, 'Oh, what will people say? What will you do? How will you look like a woman?' And I think being in the LGBTQ community has helped in that sense. Whether it is the community or that whole mindset that I've lived my life true ... I mean, I look exactly the same other than my tiny breasts are missing. I've looked exactly the same. I've always dressed androgynously.

Nancy's statement highlights that decisions of mastectomy without reconstruction are not always rooted in expected gender norms and how the LGBTQ+ community has allowed her to present her gender in neutral ways. Her comment also draws attention to the fact that women's breasts vary in size and therefore are not always "seen" even before breast cancer surgeries.

Several of the women that I interviewed found that the decision to "go flat" was also impacted by their being a member of the LGBTQ+ community. The community that one belongs to can greatly impact the level of acceptance one receives for looking "different." In other words, because of the diversity of the group, there is an understanding that "being a woman can look a lot



of different ways” (Emily). Skylar speaks to the fluidity of identity that diversity allows for when she commented, “I think for me, having played with gender throughout my life and having explored sexuality, it was more a space where I could reclaim how the world saw me.” In a similar tone, Samantha spoke of the impact of her lesbian identity on deciding to “go flat” when she said,

I’ve been out since I was 21. I’m not the most feminine girl in the world, but I’m not butch by any means of the word. So for me, I wasn’t worried about that aspect of it or of not having [breasts] there.

Samantha keys in on how being a part of the LGBTQ+ community created a space for her to feel less pressure to conform to traditional gender roles. Iris also spoke of how her being a part of the LGBTQ+ community impacted her decision to “go flat” because there was less pressure to conform when she explained, “Yes, I do think that maybe it is related to the kind of people I hang out with. I tend to hang out with more liberal, left-wing, earthy types.” Wendy reiterates this point when she said,

I also think the gay community is much more embracing of the diversity of different body types, all kinds of different bodies. The beauty standard is not as strict in the gay community as it is in the hetero community. So I think it definitely made me less afraid [to “go flat”].

These women’s statements emphasize how one’s social belonging within a diverse group like the LGBTQ+ community can be liberating for gender expressions and embracing of many body types.

The transgender community has also impacted the decisions of some lesbians to forego reconstruction. By seeing transgender individuals modify their bodies in ways that allow for a change in gender presentation, some lesbians are embracing flat chests as just another way to

present as a woman. JC, who had a single mastectomy without reconstruction, acknowledges this idea when she said,

So many of my friends have transitioned or changed their bodies in different ways, some for medical reasons, some for other reasons. So in my [LGBTQ+] community, you know, having a different kind of body is not a big deal ... I live in a world where nobody gives a \*\*\*\* and I certainly don't give a \*\*\*\* so I feel like having one breast is kind of cool. It's kind of special.

She goes on to recognize how where one is located, geographically and historically, can further impact this access to LGBTQ+ communities and the diversity they hold. She acknowledges her location in a major city (New York), as well as the social justice advocacy being done, that has led to being able to live among such diversity. She continues to acknowledge her privilege when she said,

I'm so grateful that I live in a culture and time and a place where I don't have to stress about those things. And I think, also, there's been a huge change in women, just in the last 10 to 15 years, about women accepting their bodies and not being apologetic about differences. And that's come from feminism, it's come from the disability community, and it's definitely come from the queer community.

While living in highly diverse cities can make looking and feeling different less difficult for some individuals, not everyone has that luxury. Some participants, including Dana who lives in the Midwest, mentioned that because she lives in a very conservative area that it was difficult to navigate her healthcare for fear of being discriminated against if she revealed her sexuality. Cara shared her similar fears of discrimination:

We were actually guided away from surgery at a smaller town, where my surgeon also practiced. They were like, ‘Actually, no, you shouldn’t go. You shouldn’t have your surgery there because there are people there who, you know, might give you a hard time. They might not let your partner in the room. So we were just really having to deal with these hurdles ... and you know, on top of the cancer, it just made everything stressful and added a layer of tension and unknown to what was already unpredictable and scary.

What the statements above suggest about the impact of sexuality on the surgical decisions of lesbian breast cancer patients is that sexuality plays a key role in the decision-making process. For some, the importance of their breasts is a vital aspect of their sexual relationships. As a location of physical sensation, the breasts are often seen as important to a lesbian relationship. Losing one or both breasts can be devastating to some women as they learn to adapt to new or different modes of intimacy. And for some, their sexuality was key to their ability to accept and embrace their new bodies due to their belonging to the LGBTQ+ community. Consisting of SGM individuals who often do not “fit in” to the heteronormative expectations of society, the LGBTQ+ community has created a location of resistance. Many lesbian breast cancer patients may therefore be able to cope more easily with their surgical decisions.

### **Flat Denial**

When making the decision about reconstruction surgery, patients are almost always directed to meet with a plastic surgeon. This meeting is to provide options to the patient about reconstruction surgery, including what reconstruction surgery entails and the different methods available to reconstruct breast mounds. Even when patients tell their surgeon upfront that they would not like to have reconstruction, they are often encouraged to meet with a plastic surgeon regardless. Iris explained that when she was diagnosed,

My surgeon mentioned reconstruction right away and said that they'd set me up with a plastic surgeon for a consult. And I had to ask, 'What if I don't want [reconstruction]' because body image has never really been a thing for me. She just looked at me and said, 'Then you're going to have a scar from your sternum to your armpit.' And if I didn't ask, I don't think it would have been brought up. And when I asked her how many women get reconstruction, she said, 'Most women your age do choose to get it.' That's pretty much all she said. So they automatically set me up for an appointment with the plastic surgeon.

Iris draws attention to two problematic assumptions that come with providers urging patients to meet with plastic surgeons regardless of the patients' desires. First, for many patients, flat denial begins in the first conversation they have with their surgeon which amounts to a dismissal of their autonomous decision-making. Second, her provider suggested that because she was of a certain age (Iris was in her 50s when diagnosed) that Iris would want to have reconstruction because other women her age have chosen to. These assumptions are dangerous because women are not a homogenous group, each woman has the right to make decisions for themselves based on their own wants and needs and not based on the expectations of medical professionals.

During a time when a patient's stress level is already elevated due to having a cancer diagnosis, it can be difficult to challenge healthcare providers about what appointments are in fact necessary versus optional. This leads to a confusing experience for many patients, as noted by Emily:

At my initial diagnosis, it was like, 'You're going to meet with the surgeon, you're going to find your surgical team. Here are your plastic surgeon referrals, go meet with them.' And I did all of that, like, because, you know, you're in that liminal space. You're like, I'll

just do whatever people tell me to do. And I was sort of skeptical. I went into those appointments like, 'I really don't know why I'm here.'

Emily's confusion, again, highlights the systematic flat-denial that is taking place in many surgical offices. She was assumed to want a reconstruction surgery and therefore needed to see a plastic surgeon. And while she felt that her decision to forego reconstruction was firm, she still saw the plastic surgeon because patients are taught to listen to doctors and follow their instructions in order to "get well."

Several individuals, including Barb, also spoke of the pressure to see a plastic surgeon, stating, "Yes, they did tell me to see a plastic surgeon. I didn't even know really that I had an option." Barb's experience is not unique and emphasizes how many breast cancer patients not only face a lack of autonomy in their surgical decision-making but even a lack of conversation about having a choice at all. This should be alarming to everyone, regardless of diagnosis or identity, because this places healthcare professionals in complete control of their patients' health by not making all medical/surgical options known and available.

Many women I interviewed shared that they chose not to have reconstruction because they did not like the options of reconstruction presented by the plastic surgeons. Some women spoke of disliking the idea of "foreign objects" (implants) in their bodies while others spoke of how their breasts felt "separate" from them since their breast cancer diagnosis. Skylar spoke to both of these concerns when she said,

I think for me, I had an awareness that implants in my body would feel like the breasts were 'other.' They wouldn't be my breasts again. They'd be something 'other' in my body. The idea of having any sort of foreign substance in my body felt more alienating and separating.

Emily also spoke to this notion of separation from her breasts when she said, “Going through the breast cancer process ... your breasts feel a little bit separate from you. You know, they tried to kill you. They were this problem.” This highlights how for many women the decision to reconstruct a part of their body that they had lost as a result of a disease led to conflicting feelings about how they might feel towards breasts that were a result of reconstruction.

Several women expressed their aversion to reconstruction because of the additional surgeries that the plastic surgeons would need to perform. The reconstruction process can require several surgeries. And while the end result may be aesthetically pleasing to some, the reconstructed breasts will rarely have nipples or physical sensation. Dana mentioned her opposition to reconstruction for just this reason when she said, “I don’t want to spend any more time in the hospital having surgeries, and the needed recovery time, just to have these mounds on my chest that I can’t even feel.” When Cara met with her plastic surgeon, she was shocked by the information he presented to her about reconstruction:

Meeting with the plastic surgeon ... and him just saying, ‘Here’s what we’re gonna do. We’re going to cut this muscle in your back and wrap it around your front and put it over an implant. It’s gonna be great. I was just like, ‘What in the actual \*\*\*\* are you talking about?’ ... it was all so invasive and so, like, rearranging my body as if my muscles weren’t in use, or like I had some sort of spare parts. It was shocking and it took a while for me to really digest what he was saying.

Cara draws attention to how reconstruction surgery can be quite invasive and damage healthy parts of one’s body in the process. These impacts on one’s health, as a result of reconstruction, are often left out of the conversations by surgeons as their goal for reconstruction surgery is appearance over function. For these providers, reconstructed breasts that look good are

more important than the ability for a woman to physically function as well as she did prior to surgery.

While decisions about reconstruction are personal decisions to be made by the patient, what is alarming is the number of patients that I spoke with that said that they were never even presented with the option to “go flat.” Wendy experienced this “flat denial” as she explains her meeting with her surgeon:

They did not mention flat to me. I had to mention it to them. They just rolled it down the track, you know. They said, ‘Well, we’ll do a mastectomy. You’ll do reconstruction.’ And I had to say that I wanted flat. It was just a train rolling down the tracks of, ‘We’re going to do this. If you take your breasts off, you get reconstruction.

Again, we see the flat denial being issued in Wendy’s experience as she is not even given the choice to “go flat.” She expresses the urgency of providers to move the patients from mastectomy to reconstruction as quickly as possible without consideration of the patient’s wants and needs.

Some individuals even experienced pushback from surgeons about wanting to “go flat” when they have one breast that is still considered healthy, or without cancer. Sasha, who chose this route, said that her surgeon “didn’t like [her] choosing to go with a double mastectomy with no reconstruction ... and the surgeon was hesitant to do the bilateral mastectomy at first because of the increased risks.” She stated that the surgeon suggested that removing both breasts would be more invasive than removing one breast because of a longer surgery and the possibility of a longer recovery. While some surgeons may express concern about performing a surgery that removes more healthy parts than they deem necessary, many do not express similar concerns about performing elective reconstruction surgeries. This shows just one more way that “flat denial”

presents itself in the treatment of breast cancer and the impact of flat-denial can have on surgical (non)decisions of women.

Not all women experience “flat denial” and their decision to “go flat” is welcomed by their surgeons. Maria mentioned that she “never felt any pressure to do reconstruction.” JC echoed this experience when she shared, “I think my breast surgeon just read me as somebody who had already made up their mind and so she didn’t push it.” Each woman who faces the difficult decision about mastectomy surgeries will experience different levels of comfort and acceptance among the interactions they have with their health care providers. Some will face challenges to their decisions, while others are embraced. The level of acceptance is further impacted by the use of language between surgeons and their patients during the decision-making process. Language can be vital to the understanding between surgeon and patient as to what exactly the patient wants and what exactly the surgeon will do. When clear language is not used, the door is left open for the surgeon to perform the surgery as they see fit with results that may be quite different from what the patient expects.

### **Aesthetic Flat Closure**

When patients *are* given the option of foregoing reconstruction, their surgeons are not always articulating exactly what that type of surgical outcome to expect. Too often, surgeons are not using language that explains exactly what the chest wall will look like after surgery. This leaves it open to assumptions being made about what the patient wants and what the surgeon will do. Many women go into surgery expecting to wake up with a chest that, while no longer having breasts, is stitched up in a way that is as aesthetically appealing as possible. The National Cancer Institute (2011) defines Aesthetic Flat Closure as:



A type of surgery that is done to rebuild the shape of the chest wall after one or both breasts are removed. An aesthetic flat closure may also be done after removal of a breast implant that was used to restore breast shape. During an aesthetic flat closure, extra skin, fat, and other tissue in the breast area are removed. The remaining tissue is then tightened and smoothed out so that the chest wall appears flat.

This means no extra skin, often referred to as “dog ears,” which are often left because of assumptions made by surgeons that the patient will change their mind about having reconstruction in the future. This extra skin will make reconstruction “easier” down the road because it prevents having to gain extra tissue by other means. This assumption is dangerous in many ways. First, the patient may be upset because the surgeon did not trust that the patient knew exactly what they wanted for their body. Additionally, patients may be devastated by the looks of the results which can lead to body image issues, anxiety, and depression.

Most of the women that I interviewed expressed that Aesthetic Flat Closure was never presented to them by their surgeon as an option. This was not a term that was being used by their surgeons to provide the necessary information on what to expect with a mastectomy surgery without reconstruction. Many women that I interviewed stated that they did not learn of the term until after their surgery. Therefore, they did not have the language to express to the surgeons what it was they wanted for their surgical results. Nancy expressed this gap in language when she said,

[My surgeon] asked me what kind of reconstruction I wanted to have. At the time I didn't know too many words to express what I wanted. I didn't want reconstruction, but I didn't know how to express I wanted to be flat.

By not providing patients with clear language to describe their options, patients risk being left with a chest that they are unhappy with. Skylar spoke of how this lack of language led to her undesirable

surgical outcome when she said,

My surgeon said, ‘Do you want to have reconstruction?’ and I said, ‘No.’ My response was ‘I want no reconstruction. I want to be flat.’ I didn’t have the language to request what I truly wanted for my surgery outcome. I am flat, but it’s not smooth. My chest is concaved in some places.

Being left with chests that do not look as good to patients as they had hoped can be quite traumatic and lead to issues related to body image such as depression and anxiety. While a flat chest may be covered by clothing when in public these women still have to look at themselves in the mirror daily and see what their surgeon has done to them. It is also important to note, that a majority of the participants that I interviewed stated that they were not provided any images of what to expect when choosing to “go flat.” This suggests that surgeons are not preparing women with the realities of what a flat chest will look like, aesthetic flat closure or not.

Many women are leaning on the internet to provide such education. Emily said that it was in educating herself online about mastectomy surgeries before her operation that she learned of the term Aesthetic Flat Closure and was able to request that of her surgeons by stating that she “wanted the most aesthetically pleasing chest.” Similarly, JC discovered the term on her own:

After the initial meeting with the breast surgeon, I went home and I was reading all this stuff. And then I was like, ‘Oh, there’s this phrase, aesthetic flat closure. So then I emailed [the surgeon] and asked her if this is what she was going to do. And she said, ‘Of course.’ Again, this statement from JC highlights the lack of knowledge about Aesthetic Flat Closure among patients due to a lack of language. Surgeons need to relay this information to patients before surgical decisions are made to prevent any feelings of displeasure related to surgical results.

Some women that I interviewed found out about Aesthetic Flat Closure online, among Facebook groups dedicated to members who have chosen to “go flat.” Sasha explains the impact of finding these groups after her surgery:

I hadn't heard that term from any provider that I'd seen. I've only seen it in Facebook groups. Oddly enough, that's the only place I've heard people mention it. I wanted aesthetic flat closure but I didn't know the wording for it at the time. I wasn't in the Facebook groups or anything so unfortunately, I don't have that, and I'm not exactly happy with my results. Sasha's experience highlights the importance of language, particularly between breast cancer patients and their surgeons. The heartbreaking aspect of flat denial, particularly in the absence of aesthetic flat closure, is that patients are expected to trust that their surgeons will leave the least amount of skin possible. Cara voices this disgust at the lack of empathy on the part of some surgeons when she said,

I never would have thought that I would have had to say, 'Don't leave extra skin.' This is what kills me, because, like, when you take your dog to get spayed, you're not telling the vet to 'please don't leave extra droopy skin hanging off.'

The slipshod job that many surgeons perform on mastectomy patients is shocking and shows that these women are seen as less than human. Because these women choose to 'go flat' it is assumed by some surgeons that the women do not care what their chests look like. That could not be further from the truth. The care of surgeons and their ability to verbalize what is to be done during surgery impacts these women for the rest of their lives.

## **CHAPTER SIX:**

### **DISCUSSION AND CONCLUSION**

In a society that places so much emphasis on how an individual should look, there is no doubt that many women who face breast cancer experience this pressure as they make their surgical decisions. Breasts play a key role in the physical aspect of heteronormative ideas of femininity as women have long been encouraged to perform their gender in a way that is appealing to the male gaze. Ideas of gender and femininity, however, vary from woman to woman. Some women lean towards a very feminine-appearing presentation of self, while others find themselves located elsewhere along the gender spectrum, perhaps presenting in androgynous or even masculine ways. This can be further impacted by one's sexuality, as we think of lesbian women and the traditional categories of "butch" and "femme." However, we have to be careful here not to present gender as a binary because it is anything but. Gender can be fluid and individuals can move along the spectrum, regardless of sexuality. However, these binary concepts still play a role in the heteronormative ideas of gender and therefore, the experiences of breast cancer patients. The decision to have reconstruction or not, after mastectomy, can be impacted by the stigma attached to the idea of a woman deciding to "go flat" and not conforming to society's gender expectations of femininity.

These expectations are highlighted in the interviews for this research when participants discussed their decisions to forego reconstruction, the pressures they faced to meet with plastic surgeons to discuss reconstruction and the lack of language provided to assure a surgical result that was pleasing for the patients who chose to "go flat."

When I asked the research participants what, if anything, they felt could have made their experience with breast cancer and the surgical decisions any easier, the overwhelming majority of participants stated that they would like to see aesthetic flat closure to be presented as a healthy, viable, and beautiful option for women. This research has found that surgeons continue to present reconstruction as the recommended option for many breast cancer patients. “Going flat,” when presented, is often a second, or less-desired option. And rarely are surgeons presenting Aesthetic Flat Closure as an option at all. Aesthetic Flat Closure needs to be presented to breast cancer patients as an equally desirable option as reconstruction surgery. Surgeons need to treat the chest of a woman who “goes flat” with the same attention to detail as they do to women who choose reconstruction. Additional, corrective surgeries to remove unwanted skin left by their surgeon should not be what these women have to deal with along their breast cancer journey. Being able to recognize that this “queering of the bodies” is not only an option, but a desired outcome of many women should be a mandatory part of surgical training.

Normalizing the idea of women with flat chests is a key aspect of creating acceptance of the decision to “go flat.” One way to do this is through the education of both medical professionals and patients. Each party needs to be aware of the surgical options that are available to them, as well as understand the language that is needed to explain each option. It would also be helpful for providers to have knowledge about how gender and sexuality can impact surgical decisions. Nancy added to this idea when she said that “literature out there would be very good for people who are on different parts of the gender spectrum.” Cara added, “No one mentions the impact of treatment on sex, on physical intimacy ... not only is it not mentioned across the board, but it’s really not mentioned for women with same-sex partners.” Education of surgeons and patients can provide the needed information about the risks/side effects of each surgical option.

Another way to normalize the idea of women living with flat chests is through visibility. Emily spoke of this need when she stated, “One of the important things is that women who are choosing to remain flat know that other women have done this, too, and that it’s actually far more common than I think people realize.” Just being able to see others that have made the same decision to “go flat” can be quite empowering to those that are in the process of surgical decision-making.

Several of the women that I interviewed belong to a handful of Facebook pages dedicated to flat visibility and individuals who have experienced breast cancer. These pages give patients an opportunity to share their stories with others, answer questions that women who are currently going through the process have, and post pictures of their surgical results. Many times, these groups are the only source of connection with others like them, who can best understand the challenges they are going through. These groups provide an avenue for these women to rebuild their autonomy by finding support among others that both acknowledge and support their feelings. These groups have even become places of advocacy where women are collectively joining forces to promote Aesthetic Flat Closure by providing much needed information about this surgical option as well as providing lists of surgeons who are known to offer and perform such surgeries for their patients.

Visibility also presents the opportunity to normalize the image of flat-chested women to society at large, particularly through breast cancer cause-marketing. While breast cancer awareness campaigns are often wrapped in pink ribbons and images of smiling, fully-breasted women, including flat-chested women in the images is an opportunity to better represent the diversity of those effected by the disease. As Wendy points out,

“[Breast cancer marketing] should look like us. We should be in the ads. Society just needs to get past this idea that [“going flat”] is something that we can’t look at, and instead can find it beautiful.”

Wendy's statement highlights the way that visibility can draw attention to how choosing to "go flat" is and can be a viable option for women with breast cancer. By acknowledging the existence of women with flat chests, who challenge the traditional notions of femininity, "going flat" has the opportunity to become a less-stigmatized surgical option.

## **Conclusion**

SGM women experience breast cancer in a unique way because of their gender and sexuality. Problematic notions of the "ideal" woman's body that represents femininity complicate how they navigate health care treatments such as reconstruction surgery after mastectomy. "SGM populations not only face sexism, transphobia, and/or heterosexism, many of them also bear the health consequences of other inequalities such as racism and classism" (Hsieh & Shuster, 2021, p. 324). Further research needs to be done that explores the identities and experiences of SGM individuals as they navigate breast cancer. Quantitative research is needed to understand the demographic statistics that represent the rates of reconstruction surgery compared to the decisions to "go flat." Further qualitative research is also needed so that the voices of SGM individuals can lead to deeper insights about the breast cancer experience. By bringing the voices of SGM individuals, a group that has historically been undervalued underrepresented in research, we can develop deeper understanding of how gender and sexuality impact lived experiences. This thesis has begun to do just that as it has shown that experiences of lesbian breast cancer patients is unique and deserves further analysis. This research benefits our society by allowing for a better understanding of how gender and sexuality impact the decisions made by SGM individuals with breast cancer. Further research would seek to examine the understanding of gender and sexuality identity of SGM individuals after a period of time having lived "flat." In other words, did their decision to forego reconstruction surgery impact their SGM identities in any way? What are the

experiences of transgender individuals who experience breast cancer? How do gender and sexuality impact their surgical decisions related to breast cancer?

Lastly, such research is needed as a source of representation for SGM individuals who have experienced breast cancer. In her book, *The Cancer Journals*, Audre Lorde stated, “[she] ached to talk to women about the experience [she] has just been through, and about what might be to come, and how were they doing it and how had they done it” (1997, p. 35). Breast cancer can be a lonely experience for anyone. The addition of belonging to a minority group can exacerbate this loneliness. Like Lorde, I, too, “wanted to talk to a lesbian, to sit down and start from a common language, no matter how diverse” (1997, p. 42). I hope that my research will provide at least a starting point for a better understanding of how SGM individuals experience breast cancer.



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## APPENDIX A

### Participant Recruitment Flyer



# LOOKING FOR RESEARCH PARTICIPANTS

HELP IMPROVE BREAST CANCER CARE BY  
SHARING YOUR EXPERIENCE

Participate in a 90-min interview that focuses on the surgical  
decisions of lesbian breast cancer patients.



#### Eligible participants

- Breast Cancer patient
- Identify as lesbian

Email: [egaines1@usf.edu](mailto:egaines1@usf.edu)

or Call/Text: (813)380-9801

Beth Gaines, MA Student  
Dept. of Women's and Gender Studies



USF RESEARCH & INNOVATION IRB Study #4223

## **APPENDIX B**

### **Interview Questions**

- 1) Tell me about yourself, your life, your diagnosis...
- 2) What role were you able to play in your breast cancer treatment decisions?
- 3) How do you feel about yourself as a woman?
- 4) How did this experience make you feel about your body?
- 5) What is your sense of being a lesbian?
- 6) Did this experience affect your feelings about / experience of sexuality?
- 7) What, if anything, do you wish your health care providers would have done differently to make your experience or decision easier for you?

## APPENDIX C

### IRB Letter of Exemption



#### EXEMPT DETERMINATION

June 2, 2022

Elizabeth Gaines  
109 West Fortune Street #3405  
Tampa, FL 33602

Dear Elizabeth Gaines:

On 6/1/2022, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY004223
Review Type:	Exempt 2
Title:	Lesbian Breast Cancer Patients Experiences of Surgical Decisions
Funding:	None
Protocol:	• HRP-503a - Social-Behavioral Protocol - Elizabeth Gaines - 5.13.22.docx

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Katrina Johnson

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IRB Research Compliance Administrator

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