

“Does That Make Me A Woman?”: Breast Cancer, Mastectomy, and Breast Reconstruction Decisions Among Sexual Minority Women

Psychology of Women Quarterly
35(3) 401-414
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DOI: 10.1177/0361684310395606
<http://pwq.sagepub.com>


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Abstract

Feminist scholars and activists writing about breast cancer care among women have highlighted the sexist and heterosexist assumptions often embedded in the medical management of breast cancer, and of mastectomy in particular. Despite these contributions, and some speculation that sexual minority women may be less interested in breast reconstruction, limited research explores sexual minority women's lived experience of mastectomy and decision making about reconstruction. Thirteen lesbian and/or bisexual women who had undergone mastectomy for treatment of breast cancer participated in individual qualitative interviews exploring decisions to have, or not have, breast reconstruction. Reasons for/against reconstruction reflected themes identified in prior studies among heterosexual women. Although participants described sexual, gender, and political identities and orientations as influences on their decision making, for most participants, experiences with physicians who encouraged reconstruction and concerns about stigmatization of illness in romantic, professional, and social contexts were also central. Findings are interpreted through feminist dis/ability, medicalization, and existential frameworks.

Keywords

breast cancer, mastectomy, breast reconstruction, sex orientation, decision making, health

Over the past 30 years, feminist and women's health advocates have contributed to dramatic transformations in popular and medical approaches to breast cancer. Included among these important changes are the legitimization and proliferation of resources for patient self-help, mutual support, and patient advocacy. However, as breast cancer has moved “from margin to center,” women affected with breast cancer confront this disease in a half-changed world, one that promotes collective breast cancer awareness while encouraging individual concealment of illness and distress (Wilkinson, 2001), leaving women to face a new set of pressures in treating and living with breast cancer. Whereas, prior to the Women's Health Movement, breast cancer was a “dreaded secret,” hidden behind euphemism and endured in silence, increasingly it has become an experience from which women are supposed to derive positive meanings, build a fortifying survivor community, and undergo beautifying transformations (Ehrenreich, 2001). The latter imperative—cosmetic recovery through post-mastectomy breast reconstruction—has been addressed in personal and political essays by feminist theorists and activists (Datan, 1989; Lorde, 1997); however, it is rarely taken up as a research question among feminist psychologists.

Lorde's (1997) account of her own experience of breast cancer was among the first to illuminate the sexism, racism,

and heterosexism ingrained in both the clinical and social context of breast cancer. She was particularly concerned with the assumption, expressed by medical professionals and breast cancer support organizations alike, that some form of replacement breast—whether through prosthesis or reconstruction—is an essential element of cancer survivorship. For Lorde, the refrain, “nobody will know the difference,” was exactly the problem, with the “mask of prosthesis” not only decrying women with mastectomies as insufficient but also reinforcing their isolation from each other and their political invisibility (Lorde, 1997, p. 62). In dominant American culture, where women's bodies are portrayed in the media as sex objects to serve heterosexual male pleasures (Ward, Merriwether, & Caruthers, 2006), it is not surprising that women are encouraged to cover up reminders

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of cancer, particularly of the breast. Indeed, breast loss is typically viewed through a male-identified lens, which assumes “that a woman’s major emotional problem is in relation to her husband or male lover” (Young, 1990, p. 204).

Feminist scholars have revealed the heteronormative assumptions embedded in the clinical and social management of breast cancer. Despite their critiques, little attention has been given to lesbian and bisexual women’s experience of mastectomy and decisions about breast reconstruction. Feminist philosopher Young (1990) suggests, “Only among lesbians is there an effort to affirm in public the possibility of a one-breasted woman” (p. 205). Young does not elaborate on this statement, which may rest on a presumption that sexual minority women are less vulnerable to the objectifying male gaze and its consequences for women’s body image. Notably, recent studies suggest that lesbians are indeed vulnerable to objectification and its consequences (Haines et al., 2008; Kozee & Tylka, 2006). Alternatively, Young may assume that being able to challenge one facet of hegemonic femininity, namely heterosexuality, may enable women to challenge its imposition in other domains, such as in the context of breast reconstruction decisions. However, limited research exists regarding lesbian and bisexual women’s lived experience of mastectomy and their decisions regarding breast reconstruction.

Sexual Minority Women and Breast Cancer Research

A recently growing literature examining lesbians and breast cancer suggests that lesbians may be at higher risk for breast cancer relative to heterosexual women, most likely due to increased reproductive and other behavioral risk factors (e.g., obesity, alcohol consumption, nulliparity; Denenberg, 1995). Although few definitive studies on prevalence or mortality are available, one study based on data collected through the Women’s Health Initiative (WHI) found that lesbian and bisexual women had higher prevalence of breast cancer than heterosexual women, despite similar mammography screening rates (Valanis et al., 2000). Several studies suggest that lesbians may be less likely to practice regular breast self-examination (Burnett, Steakley, Slack, Roth, & Lerman, 1999; Ellingson & Yarber, 1997).

Findings on medical breast cancer screening have been mixed, as observed in a recent review of health disparities among lesbians with cancer (Brown & Tracy, 2008). Whereas some studies found that lesbians were less likely than heterosexual women to have had a recent mammogram (e.g., Cochran et al., 2001) or clinical breast exam (Diamant, Wold, Spritzer, & Gelberg, 2000), another found lesbians were more likely to have had a recent mammogram (Aaron et al., 2001). Valanis et al. (2000) found notable differences between subgroups in their study, with *lifetime lesbians* (sex only with women ever) having the lowest rates of mammography screening in the last year compared to heterosexual, bisexual, *adult lesbians* (sex only with women aged over 45 years), and

women who never had sex as an adult, with adult lesbians reporting the highest rates among these groups. Their findings suggest a need for more nuanced analyses of screening behaviors among subgroups of sexual minority women.

Discrimination and bias in health care settings based on sexual orientation can affect patients’ willingness to access health care, as well as the quality of health care they receive (Dean et al., 2000). In a study of disclosure of sexual orientation among sexual minority women with breast cancer, Boehmer and Case (2004) found that, universally in their sample, physicians did not ask patients about their sexual orientation, and a significant portion of their sample (28%) did not come out to their physicians. This neglect is particularly important in light of research finding that, among sexual minority women with breast cancer, openness about sexual orientation was associated with lower levels of emotional distress, although discordance in level of disclosure between patients and their partners was associated with greater distress (Boehmer, Freund, & Linde, 2005). Moreover, Matthews, Peterman, Delaney, Menard, and Brandenburg’s (2002) focus group study comparing lesbian and heterosexual breast cancer survivors found that lesbian survivors reported less satisfaction with their treatment compared to heterosexual women.

Despite evidence of health care biases, a lesbian identity may also be a source of resilience for women affected with breast cancer. For example, studies have found that lesbian breast cancer patients reported fewer body image problems (Fobair et al., 2001) and less concern about appearance (Arena et al., 2006), as compared with heterosexual breast cancer patients. These findings are consistent with trends in research on body image among healthy lesbians. A recent meta-analysis found that lesbians may be slightly more satisfied with their bodies than heterosexual women, albeit only among studies comparing women of comparable weight status (Morrison, Morrison, & Sager, 2004). Arena et al.’s (2006) study, which compared 39 self-identified lesbians and 39 heterosexual women recently treated for breast cancer and matched by age, ethnicity, and disease characteristics, found that lesbian participants reported lower levels of sexual concern and less disruption in sexual activity. In contrast, Fobair et al. (2001) found no differences in mood, sexual activity, or relational issues in their study comparing 29 lesbian and 246 heterosexual women with breast cancer.

Understanding Breast Reconstruction Decisions

A recent study using the Surveillance, Epidemiology, and End Results (SEER) database found that approximately 42% of women diagnosed with breast cancer in the United States between 1998 and 2003 underwent unilateral or bilateral mastectomy (Tuttle, Habermann, Grund, Morris, & Virnig, 2007). Most women undergoing unilateral or bilateral reconstruction have the option to have breast reconstruction through either implant surgery (saline or silicone) or tissue

transfer surgery, which uses a woman's own body tissue to recreate a breast mound. Reported rates of reconstruction after mastectomy vary considerably, but across all epidemiological studies, rates are less than 50% (Alderman, McMahon, & Wilkins, 2003). Rates of reconstruction vary by age, geographic region, and race/ethnicity (Morrow, Scott, Menck, Mustoe, & Winchester, 2001). Currently, there are no known epidemiologic data available regarding rates of reconstruction, specifically among sexual minority women.

Although significant claims are made about the psychological benefits of breast reconstruction within the medical community (e.g., Ceradini & Levine, 2008), there are few well-designed and controlled studies comparing outcomes for women with and without post-mastectomy breast reconstruction. A meta-analysis of 40 studies exploring psychosocial outcomes of breast-conserving treatment (BCT) versus mastectomy found modest advantages for BCT across outcome variables. Among the studies reviewed, two compared psychosocial outcomes among women treated with BCT versus mastectomy with reconstruction, one which found advantages for BCT in terms of body image and satisfaction, and one which found no differences between the groups (Moyer, 1997). Similarly, a more recent study comparing outcomes among patients receiving BCT, mastectomy alone, and mastectomy with reconstruction surveyed 1–5 years post-diagnosis as part of a large-scale study ($n = 1,957$) of sexuality and intimacy among breast cancer survivors found no differences in emotional, social, or role functioning across patient groups, although women in both mastectomy groups complained of more physical symptoms related to their surgery (Rowland et al., 2000).

One available prospective study conducted in the United Kingdom ($n = 103$) found no difference in levels of satisfaction with reconstruction decisions across surgical groups, and no significant differences in psychological distress across groups (Harcourt et al., 2003). A more recent prospective study of women with early stage breast cancer ($n = 258$)—conducted at a comprehensive cancer center in the United States comparing mastectomy with reconstruction, mastectomy without reconstruction, and BCT on aspects of psychosocial adjustment and quality of life (QOL) at 1, 6, 12, and 24 months post-surgery—also found similar patterns of psychosocial adjustment across the three groups. In the short term, women receiving BCT reported more satisfaction with chest appearance and greater health-related QOL, with all three groups showing significant improvements in psychosocial adjustment and QOL at 2-year follow-up (Parker et al., 2007). In both studies, women receiving mastectomy with reconstruction were younger than women receiving mastectomy alone.

In a study of decision regret following breast reconstruction in Australia, Sheehan, Sherman, Lam, and Boyages (2007, 2008) described the majority of study participants as reporting either no regret (52.8%) or mild regret (27.6%), with a substantial minority (19.5%) reporting moderate to

strong regret. Regret was predicted by factors such as psychological distress, negative body image, and low satisfaction with preparatory information. Altogether, these studies, none of which report participants' sexual orientation, suggest similar outcomes in terms of psychosocial adjustment, QOL, and decision satisfaction among patients with and without breast reconstruction, suggesting that women's surgery decisions may be best guided by their own individual preferences.

To date, there has only been one known study examining breast reconstruction decisions among sexual minority women. Based on interviews conducted with 15 sexual minority women undergoing mastectomy for breast cancer (eight with and seven without reconstruction), Boehmer, Linde, and Freund (2007) concluded that sexual minority women prioritize body strength, survival, and physical functioning over outward appearance in their reconstruction decisions. They found that, among women in their study, considerations regarding breast reconstruction were "rooted in a value system and body image shaped by their sexual minority identity" (p. 464). As the first known study to consider reconstruction decisions among sexual minority women, their project represents an important contribution. However, although their findings particularly deepen our understanding of influences on sexual minority women's decision *not* to have reconstruction, they are less informative about sexual minority women's decision to *have* reconstruction.

The Present Study

Breast cancer has the potential to destabilize certain taken-for-granted meanings regarding gender, sexuality, and identity in relation to the body (Sedgwick, 1994). Perhaps for this reason, breast cancer has become a context in which gender is both "produced and policed," with the "hyper- and heterosexualization" of breast cancer now ubiquitous (Jain, 2007, p. 506). Breast reconstruction—alongside pink ribbons, "awareness bras," and "shop for the cure" events—represents one of the clearest manifestations of such gendered production and policing. However, many women opt not to have reconstruction after mastectomy, suggesting that opportunities do exist for resistance in response to such body "normalizing" in(ter)ventions. As Young (1990) hypothesizes, and Boehmer et al.'s (2007) study *may* suggest, lesbian and bisexual women may be especially capable of navigating such resistances. Through the present study, we examine the processes through which sexual minority women negotiate concerns regarding appearance, sexuality, and identities (e.g., sexual, professional, and illness identities, among other intersecting identities and roles) in the context of breast reconstruction decisions. Building on the work of feminist activists (e.g., Batt, 1994; Lorde, 1997), as well as writings by feminist psychologists such as Datan (1989) and Wilkinson and Kitzinger (1993), we were particularly interested in: (a) how

participants approached their decision making and described their feelings about breast loss and reconstruction; (b) how breast loss was framed by participants' communities, including their medical treatment team, support groups, friends, and lovers; and (c) how sexual identity, among other key identities, affected women's decision making about reconstruction and adjustment to cancer.

Method

Participants and Recruitment

Participants were 13 lesbian and bisexual women who had undergone single or bilateral mastectomy for treatment of breast cancer in the past 7 years after implementation of the Women's Health and Cancer Rights' Act (WHCRA). The WHCRA, implemented in 1999, mandates that if a group health plan, insurance company, or health maintenance organization (HMO) covers mastectomies, the plan must provide certain reconstructive surgery and other post-mastectomy benefits. Participants were recruited through a newsletter of a New York City-based organization serving lesbians, bisexual women, and transgender (LBT) people as well as caregivers affected by cancer, and through a posting on an online community board for young women affected with breast cancer that includes a discussion thread on lesbian, bisexual, and transgender topics. We recruited women undergoing mastectomy post-WHCRA so that cost and related concerns would be less likely to influence women's decisions and access to reconstruction, although these topics were explored in each interview (see Appendix for interview protocol). Efforts were made to recruit women with and without breast reconstruction. Interested participants called or e-mailed the senior author to learn about the study and to schedule their interview.

Participants ranged in age from 29 to 56 years (median = 44.5); identified predominantly as lesbian ($n = 11$) and as White ($n = 12$). Participants were highly educated, with all reporting at least "some college" education, and eight holding a graduate or professional degree, whereas income (reported as "total annual family income") was more varied (median = \$70–89,999). Five of thirteen participants reported income below \$50,000, and two reported income less than \$20,000. These two participants were insured through Medicaid, whereas all other participants were insured through an HMO, group, or private plan. Seven participants were involved in a "long-term committed relationship," five were single, and one was divorced from her long-term female partner. Participants' cancer stage ranged from zero (noninvasive breast cancer) to IIIB, with most ($n = 9$) affected with early stage (0–II) breast cancer, ($n = 3$) with stage III or higher, and one who was never informed of her stage. The median time since mastectomy was 17 months (range = 7–82 months). Eleven of the thirteen had reconstruction, and two did not.

Procedure

In-person interviews lasting approximately one hour were conducted either by the senior author ($n = 8$) or by one of three female doctoral students involved in the lead author's research group, whose ethnicity was matched with the participant's (two White, one Latina; age range = 25–28). Interviews took place in a private interview room in a university building or in an alternative private location chosen by the participant (e.g., their home or work office). Interviews were audio-recorded, and participants were compensated \$50 for their time and travel expenses. Participants were asked the following types of questions: Tell me how you decided to have, or not to have, reconstruction after your mastectomy? What did your physician tell you about breast reconstruction? Who else did you speak with about your decision? What were the most important concerns for you in this decision? How, if at all, do you think your sexual orientation influenced your decision? (See the Appendix for the complete protocol.)

Data Analysis

Our aim was to identify key themes in sexual minority women's experience of decision making about breast reconstruction that can inform a feminist analysis of this issue. Analysis was conducted using a "theoretical" version of thematic analysis (TA; Braun & Clarke, 2006). TA is "a method for identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). As an approach, it involves closely reading interviews, generating codes, and identifying key themes. The techniques of TA are common to many approaches to qualitative analysis; thus, TA has been described as a foundational method (Braun & Clarke, 2006). TA can take different forms; in a *theoretical* TA, the analytic process is driven by particular interests of the researchers. Our analysis is informed by theoretical approaches to breast cancer within feminist psychology, particularly as it intersects with work in existential psychology, disability studies, and related fields.

Each interview was audio-recorded and transcribed verbatim by a trained graduate student. A subset of the initial transcripts were read in their entirety by both authors, who worked independently to develop an initial set of codes, which were then merged to create a revised set of codes and key themes that seemed a "best representation" of the data. Key themes were modified and elaborated through the constant comparative method, used throughout the analysis to rigorously compare emerging codes and themes with our collected data. Our goal was to conduct interviews until we reached saturation, or informational redundancy. Although saturation was achieved with regard to our key themes among the subsample of women who underwent reconstruction, the small size of our subsample of two women without reconstruction limits our understanding of this subgroup. Despite extensive efforts, we were unable to reach additional women

without breast reconstruction for participation. An earlier draft of our paper was sent to interested participants, whose feedback was incorporated into the manuscript. All names presented are pseudonyms to respect privacy.

Results

The purpose of our study was to understand how sexual minority women negotiate concerns about appearance, sexuality, and identity in the context of breast cancer and breast reconstruction decisions. We begin by presenting women's self-reported reasons for having, or not having, reconstruction. Next, we discuss the processes and contexts through which these decisions were negotiated, particularly encounters with medical professionals and support groups. We illustrate how multiple identities—professional, political, sexual, and gendered identities—shape women's reconstruction decisions. Finally, we situate findings regarding body and beauty norms with possible existential and social psychological pressures for breast reconstruction.

Reconstruction Decision Making

The majority of participants in the current study opted to have reconstruction, with self-reported reasons for reconstruction echoing those reported in prior studies among (presumably) heterosexual women (e.g., Reaby, 1998). In the current study, women chose reconstruction for reasons such as desiring symmetry, avoiding external prostheses, wanting to feel “whole,” and wanting to look “normal.” Additionally, for some women, breast reconstruction was linked to notions of recovery and of transforming a once-sick body into a once-again healthy body. One participant stated: “I was not about to be flat-chested, and it's not even like if you have a double mastectomy that you have a beautiful, regular, human-looking body. You have these, like, concave areas . . . you look sick and I didn't want to be sick” (Sara, lesbian, age 29, Stage IIB, autologous tissue reconstruction). Whether participants were recovered, recovering, or still battling illness, Western culture's emphasis on “seeming” over “being” (Bourdieu, 1984)—or rather “being” by “seeming”—encourages the use of breast reconstruction to create a body that represents wellness, even if the surgery itself is linked with further bodily risk and degradation.

Several participants connected reconstruction decisions with legacies of breast cancer in their family. Breast reconstruction was discussed by two different participants as a way to differentiate their own experience with breast cancer from their mother's experience. Sara describes her mother, who developed breast cancer when Sara was a young girl, as “always miserable” after her single mastectomy, adding that she “always felt really self conscious about it.” Sara wanted to do things differently: “I guess from all of her unhappiness I was like, ‘I'm not gonna [not reconstruct].’ Also, it just seemed like her trying to put in the prosthetics and bathing

suits . . . so I was like, ‘I wanna be able to have breasts.’” For Maura, to “do something else” held the possibility in her mind of having a different outcome than her mother, who died at a young age of breast cancer.

My mother was diagnosed at the age of 42 and she died at 46 and she had a radical mastectomy. . . . I had a vivid memory of what her body looked like The reason I didn't choose doing nothing [was] because my mother hadn't done anything, and she had a very bad outcome. It's like superstition, right? So she did nothing. . . . her body had an indentation where the underarm was and then she had this big scar that went straight down her body. This is the memory I had of what she looked like, so I opted to do something else (Maura, lesbian, age 53, Stage I, autologous tissue reconstruction).

Whereas most of the women in the current study elected to reconstruct, two did not. Similar to participants' reasons for reconstruction, reasons for not having reconstruction reflected themes identified in prior studies: concerns about implants and wanting to avoid further surgery and pain. As one participant explained:

So really, my only options were having foreign items of some kind or other implanted, and that being something that I've always, before being diagnosed, was never keen on. You know, because there's too many rejections or complications and things break down or they rupture and then you have another surgery (Cyndie, lesbian, age 37, Stage I, no reconstruction).

The prospect of additional surgery, accompanied by additional pain, and the threat of future surgeries, if complications should arise, was a concern for both of these participants. Rebecca said:

I also spoke to a number of women who said that it was either painful or uncomfortable and I didn't want to have problems with it. . . . I was 36 at the time and the implants, as I'm sure you know, will often fail every 10 or 15 years. . . . Do I really want to commit to a major surgery every 10 or 15 years for the rest of my life? I plan on living at least another 50, thanks very much. So that's like four major surgeries in my lifetime; just to do something that might be restricting or painful, or you know, inhibit my ability to be as active a person as I am. And it just was very unappealing (Rebecca, lesbian, age 37, Stage II, no reconstruction).

Most participants, both with and without reconstruction, affirmed their decision during the course of the interview, indicating they would likely make the same one again. For example, as Dana commented about her decision to have reconstruction, “It was very clear to me that . . . I did not take the wrong path” (lesbian/bisexual, age 49, Stage II, implant reconstruction). Another participant emphasized the importance of standing by your decision, whatever the decision is: “It doesn't matter what a woman's choices are, as long

as she is like 100% committed to it . . . Make the choice and stand behind it and move on, what's next. Okay, I chose to reconstruct, so it's not going to look perfect, okay, there it is" (Jeannie, lesbian, age 47, Stage III, implant reconstruction).

Gender Policing and Medicalization

Whereas most participants affirmed their surgery decision, most also faced considerable pressure, both implicitly and explicitly, to have reconstruction. Physicians framed breast reconstruction as a "natural" step in treatment following mastectomy. One participant stated, "I think they all assumed that I would want it and they didn't really talk about not having it" (Stephanie, lesbian, age 32, Stage I, implant reconstruction). Similarly, others felt that the full range of options, including bilateral mastectomy without reconstruction, were not discussed:

The oncologist and the case nurse didn't really talk to me about not doing any reconstruction, which was an option. And had they shown that I could have maybe removed both breasts and had them take care of my chest in such a way where it could still look good—which I don't know if that is possible or not—then I would have considered that (Jeannie, lesbian, age 47, Stage III, implant reconstruction).

Another woman said: "I felt that if I have both . . . taken out, why do I need reconstruction? She said no, the doctor, because of this, that, and whatever, you know. Trying to convince me. And finally she did" (María, lesbian, age 56, not informed of cancer stage, implant reconstruction).

Shared decision making between patients and health care providers is increasingly advocated within the medical community as an ideal approach to patient care. Shared decision making is viewed as a particularly important process when patients have more than one treatment option, when each option has both advantages and disadvantages, and when there is no right choice (Charles, Gafni, & Whelan, 1997), all of which are conditions that characterize the breast reconstruction decision. Physicians may compromise the shared decision-making process by communicating a belief that they know what is best for a particular patient. The suggestion, whether implicit or explicit, that breast reconstruction is the "natural," inevitable, or best choice for all eligible patients compromises shared decision making and, even worse, may lead to downplaying potential risks. María experienced this minimizing of risk in communications with her physician: "Well, I know the benefits. We talked about the benefits. We didn't really talk about the risks. Or if we did, I don't remember" (María, lesbian, age 56, not informed of cancer stage, implant reconstruction). Another participant, who had an autologous tissue reconstruction, described her conversation with her physician about risk and complications:

I asked "Will this affect me? Will I not age well?" And they said, "You won't be able to do sit-ups." At the time I didn't care but I had no idea I wouldn't be able to *sit up*. It was the most invasive thing I could have done, and aside from the whole emotional whatever there is of losing a breast, I had complications. I developed a hernia . . . they had to open me up and do the whole thing again (Amy, lesbian, age 48, Stage 0).

Although breast reconstruction is an elective procedure, women felt that they needed to justify to their doctors their reasons for *opting out* of surgery. Reasons for opting in, however, were viewed as self-evident, particularly for those judged to be good candidates for surgery. Helen described being talked into getting reconstructive surgery:

[My oncologist] brought up reconstruction with me. I had very little interest in it. She was gung ho about it and said, "Go to the plastic surgeon anyway." I said, "I don't want to. I'm not interested in reconstruction." . . . The plastic surgeons said to me, "You're the perfect candidate for reconstruction." So now I was sort of getting buttered up here. She's telling me I'm young and he's telling me I'm the perfect candidate. Then he said, "Because you don't sag, I can give you a breast that will look just like that breast." I just kind of shrugged and said, OK (Helen, lesbian, age 52, Stage I, implant reconstruction).

For one participant, attempts to approach decision making through weighing the pros and cons, gathering information, and careful reflection were even thwarted within her recovery community. At first unsure about whether to have reconstruction, she discussed the reaction of her support group to this uncertainty:

But I went to a group . . . and part of that group was to support me through being diagnosed, and the chemo, but also because I was trying to decide. At that point then I was like, "Well, I need to really think this out. Do I really want to have a bilateral mastectomy? And if I do, do I want to have reconstruction?" I didn't want to go blindly in making those decisions and then have to look back and say, "Did I really make the right choice?" So I went into this group, and everybody in the group had had either one or two breasts removed, and had reconstruction surgery . . . Interestingly enough, the women were shocked that I was trying to decide, that I was weighing the odds . . . I was actually surprised at the people's reaction to me not being sure. And they were trying to talk me into it (Dana, lesbian/bisexual, age 49, Stage II, implant reconstruction).

Although all participants' mastectomies were the result of breast cancer, a medical condition, Helen's and Dana's experiences illustrate the extent to which breast loss itself has come to be viewed as a medical condition. Although the increased availability and range of options for breast reconstruction should provide women with more

post-mastectomy choices, paradoxically, the option to *not* reconstruct is diminished, consistent with patterns of medicalization in other domains (e.g., childbirth and hormone therapy; see Conrad, 2007).

For women already overwhelmed by the news of a cancer diagnosis, the intensity of treatment regimes, the cascade of decisions involved in breast cancer treatment, and the fear of decisional regret (Col, Duffy, & Landau, 2005), “opting out” in the face of such questioning from medical professionals, and even support group members, can be a formidable prospect. It is noteworthy that, in the latter case, Dana did not attend a lesbian and bisexual women’s support group, noting that “nobody identified, and I didn’t get a sense” of whether there might be other lesbian or bisexual group members. She added that she did not personally feel safe coming out to the group. Upon reviewing an earlier version of this manuscript, one participant remarked that Dana’s experience would have been less likely to occur in the lesbian and bisexual women’s support group that she had attended, where she felt there was considerable openness to women’s different reconstruction decisions.

Negotiating the Politics of Breast Reconstruction

Ideally, decisions about breast reconstruction are rooted in patients’ personal values and preferences—qualities that are always already shaped by the cultural milieu—as well as in their personal valuation of the risks and benefits of surgery. However, in a “pinkwashed” breast cancer culture, women who question whether or not to have reconstruction may be marked as oppositional, as making a political statement with their bodies. On the decision of whether to appear “one-breasted” in public, Jain (2007, p. 512) notes: “It seemed implicitly like a political statement to not wear a prosthesis, even when the only ‘politics’ was in having neither prosthesis nor a second mastectomy rather than in any actual action. I did not want to be coded as making some permanent radical political statement.”

Women in the current study also experienced ambivalence about the post-mastectomy options available to them and the identity consequences for each. For example, Dana had reservations about becoming “the type of person” who gets cosmetic surgery. Moreover, as Dana had already undergone prophylactic oophorectomy due to a family history of ovarian cancer, the decision about reconstruction brought into question the meaning of her body and what physical attributes were essential to being a woman:

Part of that was political, like well, what are our breasts? And, does that make me a woman? And, what will my body feel like with implants? And it’s different now than it was 30 years ago, because now women get augmented breast surgery, and there’s this whole thing about that, the type of the person who does that, and why they’re doing it, though mine is

completely different (Dana, lesbian/bisexual, age 49, Stage II, implant reconstruction).

Relating to the politics of breast reconstruction, participants like Dana are caught in a “catch-22,” such that women who decide against reconstruction risk portrayal as desexualized women, whereas reconstruction, through its association with cosmetic breast surgery, can feel like an endorsement of women’s objectification. Through either route, these dual controlling images of women can threaten women’s sense of sexual agency.

The politics of breast surgery—whether augmentation or reconstruction—emerged as an issue in several interviews. The increase in positive images of mastectomy in the past 30 years (albeit still too few and far between), such as Metzger’s (1977) “The Warrior,” her self-portrait with a mastectomy and the tree branch she had tattooed around the scar, has enabled an empowering alternative to breast reconstruction. However, women such as Dana who admire the one-breasted warrior found that in coping with feelings related to cancer and its bodily impacts, resistance is harder than the proud, bold image suggests:

I used to have a calendar of a woman who had a bilateral mastectomy, and had a tattoo, and she was standing on a mountain with her arms [out], so she empowered herself, even though she didn’t have breasts, and was still a woman. And then it was also flipping me out because I didn’t have ovaries, and I was going to have my breasts removed, and am I a woman? . . . I had to address all those feelings because I just wanted to go in making a decision being firm about what I did, and knowing what the whole process involved (Dana, lesbian/bisexual, age 49, Stage II, implant reconstruction).

Dana viewed “The Warrior” as an empowering alternative, an emancipatory image. However, over time this iconic image had also come to represent a “right” way for strong women to handle cancer, and some participants expressed feelings of inadequacy for not choosing that option. As Amy laments, “I *should* have just been able to have that lightening bolt scar and call it a day and someday *maybe* meet somebody lovely who it wouldn’t matter to” (Amy, lesbian, age 48, Stage 0, autologous tissue reconstruction). Amy, whose long-term relationship ended during the course of her cancer treatment, was feeling especially vulnerable about the prospect of dating after her mastectomy.

One participant expressed hope that the influence of the women’s movement will make it easier for the *next* generation of women to opt out of reconstruction, even if this was not the option for her:

There’s a whole wave of new direction women have been going in general. [Society will] value us for our mind and for our contributions to society, not just how we look. So I think that this disease will catch up and the choices maybe will catch up with that thinking. For those reasons, and that in that way, I’ll be like a dinosaur, but that’s okay (Jeannie, lesbian, age 47, Stage III, implant reconstruction).

For Jeannie, who was single and also looking to return to work after significant time off due to cancer treatment, aesthetics trumped politics. “I mean, my choice was completely aesthetic . . . it’s not a better or worse choice than any another. It’s just the choice that I made.” Interestingly, what Jeannie framed as an aesthetic choice, Caroline framed as a political one. For Caroline, reconstruction put her in the “power seat,” giving her the control and choice to decide with whom, and when, she would share her cancer history. Nonetheless, Caroline was cognizant of the beauty politics surrounding her decision, noting, “There is part of me that likes them better than the old ones. I like the way I look better now and I feel like there is some amount of betrayal of my sisters” (Caroline, bisexual, age 42, Stage II, implant reconstruction).

Deconstructing and Reconstructing Womanhood

A diagnosis of breast cancer is a major health crisis for a woman; however, breast cancer is more often portrayed as a cosmetic crisis. That breast cancer is viewed as a threat to women’s beauty, and thus to her female identity, is underscored by a review of the titles of several recently popular breast cancer memoirs, such as *Crazy Sexy Cancer Tips* (Carr, 2007), *Why I Wore Lipstick to My Mastectomy* (Lucas, 2004), and *Pretty Is What Changes* (Queller, 2008). In Datan’s (1989) essay, *Illness and Imagery*, she discusses the disproportionate focus on cosmetic appearance and reconstructive options in the literature she received after her mastectomy. The implication, according to the literature she received, is that breast loss is not only a physical change to one’s body but a removal of one’s sexual identity and attractiveness. As Datan (1989, p. 185) states, “One is victimized not by a disease but by its cosmetic consequences: the threat of a desexualized body.”

In Western culture, breasts are signifiers of both sexuality and gender identity. For a few participants, sexual orientation and identity had already necessitated challenges to hegemonic femininity and, perhaps consistent with Young’s (1990) contention, it may have been easier for them to question the medical community’s mandate to reconstruct. As one participant stated:

There is a possibility that subconsciously it was easier for me to make the decision to have the mastectomy versus the lumpectomy because the trend—if you want to be PC [politically correct]—is that lesbian women are supposed to be less concerned with doing the whole system-societal, looking pretty and whatever. So maybe in some level subconsciously that could play a role (Cyndie, lesbian, age 37, Stage I, no reconstruction).

Another participant, Rebecca, came to accept this aspect of herself through enacting what Butler (1990) might call a gender parody or performance:

I always felt like my breasts were a costume, because they were so big and they were—kind of campy. I got used to them, to the point where I actually really liked them and dressed them up and you know, flaunted cleavage and all that kind of thing ‘cause it was fun. But I never really felt that, at core, I was a big boob person. You know? (Rebecca, lesbian, age 37, Stage II, no reconstruction)

She later adds, “I kind of felt [that] I got a great rack, I had fun with it and I kind of didn’t need to experience that again. Been there, done that now I can do something else.” This view of gender as performance may have protected her from the notion that mastectomy constituted a threat to her identity. Indeed, whereas reconstruction is often offered as a way for women to restore their sense of self after illness, Rebecca offers a counternarrative of her breast loss, reframing mastectomy as a way to “liberate identity from bodily constraints” (Herndl, 2006, p. 226). Although Rebecca’s response was not common among participants, she is not the first to embrace new possibilities of embodiment after cancer. Sedgwick (1999, p. 71) acknowledges both the trauma and possibility of breast cancer when she writes: “I have never felt less stability in my gender, age, and racial identities, nor—anxious and full of the shreds of dread, shame, and mourning as this process is—have I ever felt more of a mind to explore and exploit every possibility.” Similarly, Ling (1999) writes about how, in the course of chemotherapy treatment, she used varied wigs as a way to experiment and “try on” different ethnic identities.

For some participants, such as Rebecca, being part of a queer community may have made challenging mainstream beauty ideals, “playing” with gender, and separating having or not having breasts from one’s personal gender identity a little easier, as was similarly noted among *some* participants in Sinding, Grassau, and Barnoff’s (2006) study of community support among lesbians with cancer in Canada. For other participants, mastectomy brought up long-standing questions and struggles between normative femininity—how one is *supposed* to look or behave as a woman—and their own self-identity as a woman.

And I think that comes from being a lesbian . . . and sort of feeling like there’s a spectrum of femininity 0 to 10, and sometimes I fall in the middle . . . I’ve never been one of those people who wanted to be a boy, or wants to look like a boy. I very much feel like a woman, I’m definitely a woman. But society says what a woman looks like, and *should* look like, and that’s how a woman should be . . . I can’t agree with it, because I can’t adhere to any of that. So there was that struggle of not wanting—I remember being 13 and being called a boy, or my girlfriends, teaching me how to walk because I didn’t walk like a girl, and how that was difficult for me because I wanted to be a girl. I was a girl, you know? Or my brothers [would] tell me I throw like a girl. But I am a girl, you know? So that whole gender, what’s-a-woman kind of thing came up, and I think just being in a world, and being a lesbian,

or self-identifying as a lesbian sort of exacerbates that. I can't imagine that a classic, heterosexual woman confronts those issues. Or if they do, not in a deeper way (Dana, lesbian/bisexual, age 49, Stage II, implant reconstruction).

Another participant, Sara, described feeling alienated from friends within the lesbian, gay, bisexual, and transgender (LGBT) community, who did not seem to grasp the circumstances of her mastectomy—as a treatment for a life-threatening cancer at age 29—rather than as a decision she was making about her identity. Sara explains:

... one of my close friends, who's also lesbian, was like, "Well, why are you having reconstruction," and I felt like that was such a weird thing to ask. I think she was thinking of all the women she knew who had the double mastectomy and had to raise all this money to have this surgery as part of their gender identity. My gender identity is of a woman entirely, I'm sad that my breasts are gone. This is not ... my triumphant identity choice to have my breasts removed. I was happy with my breasts. I'm very sad that I'm losing them ... When I take off my clothes I want to have the form of a woman (Sara, lesbian, age 29, Stage IIB, autologous tissue reconstruction).

Similarly, Jeannie describes feeling taken aback when, "I had somebody ask me one time, since I was a lesbian why was it such a big deal to lose my breast?" Her response, to this person, as well as to our question of how her sexual identity affected her reconstruction decision, was, "First I'm a human, and next I'm a woman, and next I'm a lesbian woman. Nobody likes to see themselves disfigured from a disease" (Jeannie, lesbian, age 47, Stage III, implant reconstruction).

Breast Reconstruction and Terror Management

In her essay, *Illness as a Metaphor*, Sontag (1990) discusses the stigma of cancer and its impact on patients' suffering. Although the stigma of cancer, or at least of certain cancers, has diminished considerably in the past 30 years, it has not entirely disappeared. Lorde (1997, p. 62) called for a politics of visibility in response to breast cancer stigma, noting, "silence and invisibility go hand in hand with powerlessness." However, as the army of one-breasted women she imagined descending upon Congress has morphed into a sea of pink sponsored by the fashion and cosmetics industries, problems such as social and employment discrimination are left to be solved by the individual, rather than through collective action. As Jain (2007, p. 505) states:

... gender signifiers offer an easier conversation topic than does mortality ... The focus on pink and breasts and comfort may be, quite simply, a convenient way to displace sheer terror: after all, what would it mean to really acknowledge—really acknowledge—the fact that 41,000 people each year die of a disease from which one literally rots from the inside

out with no cure while so many known causes continue to be pumped into the environment?

Even mental health professionals may prioritize discussion of cosmetic concerns to defend against real conversations about illness and death. As one participant noted, "A psychiatrist I had been seeing, when I told him about the cancer diagnosis, his response, his *immediate* response to hearing I had cancer, was 'I hear they can do wonderful things with reconstruction'" (Helen, lesbian, age 52, Stage I, implant reconstruction).

Breast reconstruction may function to "protect" others—friends, family, lovers, colleagues, strangers—from confronting reminders of mortality. As Stephanie, a participant who opted for implant reconstruction, remarks:

I just wasn't willing to not have reconstruction because I felt like my career was gonna be so much harder as it was having had cancer ... I'm not that "out" within the [acting] industry about cancer because they don't really look too kindly on that ... it means illness, [a] liability for them. They cast you and you get sick. It's very ... the whole entertainment industry's so focused on youth ... I'm "out" about being lesbian certainly more than I am about cancer (Stephanie, lesbian, age 32, Stage I, implant reconstruction).

Like Stephanie, Jeannie, who had lost her job, along with her health insurance, just before her cancer diagnosis, discusses her fears of finding work after cancer:

How are you going to get a job and not tell people you have cancer? ... How do you continue to get treatment and not let people know. Because whether it's legal or not, they'll find a way. If they don't want to hire you, they won't. I know it's illegal ... it [can] still happen.

She similarly contrasts her fears of "coming out" about cancer with her (lesser) concerns about "coming out" as a lesbian, at least in terms of employment discrimination. Jeannie notes, "... the gay thing has usually been more of a water cooler issue than getting in someplace."

Whereas some participants discussed the need to hide markers of illness for work reasons, others worried about how cancer would impact finding a relationship. As Caroline noted:

I do have concerns, not just about body image but about like, you know, whether people want to get involved with someone who is a cancer survivor ... I think it is going to be harder for me ... when I start dating again, it is going to be with people who don't know me or know about that part of me (Caroline, bisexual, age 42, Stage II, implant reconstruction).

Dana described how her anxieties about dating after breast cancer were reinforced by a conversation with a friend:

When I was first diagnosed, I was having dinner with a friend who was a medical student at the time, and she started telling

me how impressed she was with this guy who was dating a woman who while he was dating her was diagnosed with some kind of cancer, and that he continued to date her. She was impressed with that. And I was appalled. And this was a medical student, someone who was going to be a physician . . . It made me feel like I was a leper or something. That somebody wouldn't want to be with me. And it really had an intense impact on me, and still does . . . sort of like there's that, "Hi, my name is Dana. I'm a breast cancer survivor and I have implants." We all come with our baggage. I just feel like I have a lot of baggage, you know? And I think sometimes that puts me off from going through the whole dating thing.

Reconstruction may function to (somewhat) allow women to distance themselves from reminders of cancer within a social milieu. It may "protect" others close to them—physicians, support group members, friends, employers, lovers—from acknowledging the patient's mortality, as well as their own. For Lorde (1997, p. 62), "the primary challenge at the core of mastectomy was the stark look at my own mortality." However, as Sara elaborated after reading an earlier draft of this paper, the pain and the scarring associated with reconstruction "has its own way of being a reminder of sickness and mortality, a daily reminder."

Discussion

There is a dearth of research on sexual minority women's experience of breast loss due to cancer. The aim of the current study was to better understand decision making about breast reconstruction among a sample of lesbian and bisexual women. Moreover, we sought to understand how sexual minority women may negotiate concerns regarding appearance, sexuality, and identity in the context of breast reconstruction decisions. In contrast to suggestions by Boehmer et al. (2007) and Young (1990), our findings suggest sexual minority women generally report similar reasons for having, or not having, breast reconstruction when compared with existing studies among presumed heterosexual women. These reasons include wanting to feel "normal" or whole again, to feel more balanced, to "forget" about cancer, to regain femininity, as well as wanting to avoid prosthesis and wanting to be able to wear different types of clothing (Reaby, 1998). Other influences on breast reconstruction documented in prior studies of presumed heterosexual women include their interactions with health professionals and prevailing surgical practice norms (Harcourt & Rumsey, 2004), all relevant in the current study. However, although participants' reasons for and influences on reconstruction reflected themes similar to those identified in studies of heterosexual women, in contrast to prior research, we found that study participants were acutely aware of and reflective about potential political readings of breast reconstruction in relation to gender identity and feminist body politics.

Several participants described substantial "gender policing" in the form of pressures both from physicians and within survivorship communities to have reconstruction, with a few noting that they might have considered bilateral mastectomy without reconstruction had it been presented as a viable option to them. The standardization of breast reconstruction, as previously articulated by Batt (1994), Datan (1989), and Kasper (1995), among others, was also ubiquitous among this sample of lesbian and bisexual women. The positive interpretation of this finding is that, in regard to breast reconstruction options, sexual minority women in our study were not treated differently than heterosexual women (although heteronormativity was noted in clinical encounters by several participants). However, the equal imposition of "the beauty myth" against women with cancer through normalization of breast reconstruction (Batt, 1994) is arguably a troubled equality.

When Young (1990) suggests that lesbians may be more likely to accept and publicly affirm the possibility of a positive one-breasted woman, she is at least partly referring to the presumed greater freedom from the male gaze. However, we contend that another privileged and controlling gaze—the "able-bodied" gaze—may be at least as important to understand women's reconstruction decisions, including the decisions of lesbian and bisexual women. As feminist disability studies scholar Wendell (1997, p. 268) writes: "In a society which idealizes the body, the physically disabled are marginalized The disabled are not only de-valued for their de-valued bodies (Hannaford, 1985), they are constant reminders to the able-bodied of the negative body—of what the able-bodied are trying to avoid, forget and ignore." Disability theorists (e.g., Banks, 2010) emphasize the socially constructed nature of disability, namely, that it arises from the interaction between bodies (and embodied differences) and an unaccommodating physical and social environment. Although many women post-mastectomy will face minimal, if any, functional impairment, disability theory's challenge to notions of the "normal" body make it particularly useful for understanding the experiences of women who have undergone mastectomy for breast cancer.

We contend that a feminist analysis of breast reconstruction, and a feminist theory of breast cancer, must extend beyond an analysis of female objectification toward an understanding of how that objectification itself is connected to fears associated with the imperfect, fragile, and mortal body. These fears can affect all women, regardless of sexual orientation. As Wendell (1997, p. 268) suggests, "Idealizing the body and wanting to control it go hand-in-hand." A related argument has been articulated by Goldenberg and Roberts (2004), whose integrated feminist and existential perspective offers an explanation for women's sexual objectification rooted in existential anxiety and terror management strategies (see also Goldenberg, Heflick, Vaes, Motyl, & Greenberg, 2009). Extending the work of existential theories, terror management theory postulates that the awareness of the

inevitability of death gives rise to the potential for extreme anxiety or terror that individuals manage through “a cultural worldview and the self-esteem derived from living up to the standards of one’s worldview” (Cox, Goldenberg, Arndt, & Pyszczynski, 2007, p. 111). According to an integrated feminist existential perspective, the female body’s more obvious role in reproduction (a reminder of her “creatureliness,” and thus mortality) may make women especially vulnerable to negative reactions to our physicality and to sexual objectification as a strategy to strip women of their connection to nature. The irony of this defense is that through the idealization and objectification of the female body, women are viewed *merely* as sexual objects.

Breast reconstruction may be a strategy used by women (and encouraged by physicians) to symbolically defend against existential anxieties, both for themselves and for others. Likewise, today’s pinkwashed breast cancer culture has transformed this potentially life-threatening illness into a symbol of femininity. The consequences for women may include a denial of their deeper anxieties through a reframing of breast cancer as a cosmetic crisis rather than as an existential one. Understanding that decisions about breast reconstruction may involve a great deal more than appearance concerns may open possibilities for discussion of these other anxieties and thus enable a broader range of responses to them. Although mental health providers working with cancer patients should acknowledge and help clients adjust to the real bodily changes experienced through cancer treatment, they must also be open to hearing patients’ deeper anxieties, whether working with clients with early or late stage cancer.

Limitations and Conclusions

The methodology of the current study precludes us from drawing conclusions about whether lesbian and bisexual women are more or less interested in breast reconstruction surgery. However, our findings do suggest that sexual minority women undergoing mastectomy face many of the same anxieties regarding breast loss as heterosexual women, perhaps, because these often represent existential anxieties masked by the culture through cosmetic concerns. Challenging the norms of cancer concealment may be difficult for women who, often already vulnerable, fear further material and relational consequences for doing so, as suggested by several participants in the current study. In the one prior known study of breast reconstruction among sexual minority women, Boehmer et al. (2007) found that their participants’ decisions for or against reconstruction were rooted in a value system and body image shaped by their sexual minority identity. Their findings are not inconsistent with our study’s results: we also found that considerations for or against reconstruction were influenced by women’s sexual and political identities. However, our findings suggest that sexual identity is not the only, nor necessarily the primary, influence on women’s decisions for or against breast reconstruction.

Sexual identity is rarely assessed and/or reported in studies of psychosocial adjustment and QOL among breast cancer survivors. Feminist identification, although not assessed in the current study, is also likely to have influenced some of our participants’ decision-making processes. This information is necessary to further understand the shared and unique concerns faced by sexual minority women affected by cancer.

Our findings are limited by several important factors. Despite our efforts to recruit women with and without reconstruction, the majority of our study participants had reconstruction. Our participants were younger than the “typical” breast cancer patient, with a median age of 44.5, compared with SEER reports indicating the median age of diagnosis of breast cancer among American women is 61 years (Altekruse et al., 2010). Younger women may have been more likely to utilize the support resources from which we recruited our sample. Surgeons are more likely to discuss breast reconstruction with younger women (Alderman et al., 2008), and younger women are more likely to have breast reconstruction (e.g., Reaby, 1998; Rowland et al., 2000), which likely influenced the emphasis on reconstruction in the current study. It may also be that women undergoing reconstruction were more ambivalent about their decision than those without reconstruction and thus more likely to be drawn to a study where they could discuss their feelings and experiences. Because we recruited primarily from breast cancer support organizations, newsletters, and online discussion boards, current study participants may have had greater support needs than other sexual minority women undergoing mastectomy who did not seek out additional social support. Alternatively, they may have been better connected within the LGBT community and more psychologically ready to utilize support resources. Moreover, because participants in our study were relatively homogenous, a majority identifying as White and living in New York City, other cultural influences, such as race/ethnicity and geography, were not readily explored but may affect patients’ decision making, and access to, breast reconstruction (Rubin, Alderman, & Pusic, 2007). Future research on breast surgery decisions and outcomes should assess sexual orientation and should make efforts to include sexual minority women who are diverse in terms of age, cancer stage, ethnicity, geography, and socioeconomic status.

The lesbian and bisexual women we interviewed all experienced a serious, life-threatening disease and underwent major surgery to treat it. Whether they chose reconstructive surgery or not, they all underwent breast loss and live in changed bodies that are marked by illness. Breast reconstruction may ease the recovery process for some and conceal one’s status as an illness survivor; however, it does not change their reality of having had cancer. Feminist breast cancer survivor scholarship has put forth the possibility—a challenge, even—of opting out of surgery. However, this opting out is currently not viewed as a neutral or equal option, but rather is coded as an inherently political act—rejections of physicians’

recommendations, of advice from breast cancer support groups, and of social norms. It can carry implications beyond simply wanting to avoid additional surgery or, like Datan (1989), prioritizing bodily well-being and fitness. Breast loss raises questions about identity and what it means to be a woman, and although the simplest antidote may be a cosmetic one—to replace the lost breast(s)—perhaps, it really calls for a redefinition and expansion of what it means to be a woman.

In this half-changed world, participants acknowledged and even idealized the one-breasted warrior portrayal of a breast cancer survivor but did not necessarily view it as an option available to them. Through highlighting the contexts and contingencies that shape breast reconstruction decisions, even and especially among sexual minority women who some suggest may be better able to resist such pressures, our goal is to expand the repertoire of options and identity positions women have after mastectomy, rather than argue for a “right,” “wrong,” or “politically correct” response to it.

Appendix

Interview Protocol

Background and Experience of Diagnosis

- What was going on in your life when you were diagnosed with breast cancer?
- How did you learn you had breast cancer?

Deciding About Breast Reconstruction

- Tell me how you decided to have (or not to have) reconstruction after your mastectomy?
- What did your physician (oncologist, surgeon, gynecologist) tell you about breast reconstruction?
- Did you meet with a plastic surgeon to discuss breast reconstruction?
- How do you feel about the information you received?
- Did you seek out additional information (e.g., from friends, family, websites, support group members)?
- Who did you speak with about your decision? What did they have to say about it?
- How, if at all, did your sexual orientation or sexual identity affect your decision?
- How, if at all, did insurance or other cost factors influence your decision?

Relationships/Body Image/Sexuality

- *If partnered:* What was your partner’s attitude toward reconstruction? How important was your partner’s opinion in your decision?
- *If single:* What were your feelings about dating/relationships after mastectomy? Did these concerns affect your decision to have (or not to have) reconstruction?

- How has the surgery affected how you feel about your body?
- How has the surgery affected your relationship? Your sex life?
- If participant has had delayed reconstruction, explore sexuality before and after reconstruction.
- How has the surgery affected how you dress?
- How has the surgery affected your relationships with other people?

Recovery and Recommendations

- How do you feel about your decision to (not) have reconstruction?
- Drawing from your own experience, what advice would you give to other women making this decision?
- What advice would you give to doctors working with women considering reconstruction?

Acknowledgments

This research was supported by research funds provided to Lisa Rubin by the New School for Social Research. We thank Mary Carol Mazza, Chakira Haddock, and Julie Trompeter for their help with data collection, and Silvia Fernandez and Leeat Granek for helpful feedback. Most of all, we extend our deep appreciation to the women who participated in this research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: This research was supported by new faculty research start-up funds provided to Lisa Rubin by The New School for Social Research.

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