

Rejection of Breast Reconstruction Among Lesbian Breast Cancer Patients

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Abstract

Purpose: After having breast cancer (BC) and being treated by mastectomy, patients typically struggle with decisions about reconstruction. It is unclear how lesbian-identified women think about breast reconstruction. The purpose of this study was to explore lesbian BC survivors' attitudes toward breast reconstruction. This study represents the first published study to analyze data from a lesbian-specific BC forum to evaluate such attitudes.

Methods: We conducted an inductive thematic analysis of breast reconstruction discussions among individuals who posted to a lesbian-specific online support forum found on breastcancer.org, the largest online support venue for BC survivors. Two hundred fifty-five users posted to the lesbian-specific forum; 53 of these users discussed breast reconstruction and were included in the present analysis. We analyzed a total of 168 posts.

Results: Our analysis revealed five important themes related to breast reconstruction attitudes as follows: (1) rejecting being defined by their body image, (2) privileging sensation over appearance, (3) believing that being breastless is protective, (4) perceiving their social context as supportive of nonreconstruction, and (5) feeling pressured by social norms to undergo reconstructive surgery.

Conclusions: Among postings in the lesbian-specific online support forum, attitudes related to the rejection of breast reconstruction were pervasive. Provider communication should be evaluated for heterosexist biases, such as the implication that breast reconstruction should be a part of a normal course of treatment. In addition, providers must acknowledge that breast reconstruction is value laden and the range of viable treatment and reconstruction options, including the decision not to reconstruct, should be presented in a nonbiased neutral way.

Key words: breast cancer, breast reconstruction, decision-making, lesbian, qualitative research.

Introduction

SEXUAL MINORITY WOMEN (SMW) are at significantly greater risk for developing breast cancer (BC) than their heterosexual counterparts. Emerging evidence suggests that lesbians and bisexual women are at an increased risk for BC not because of their sexual orientation, *per se*, but because some risk factors and barriers to screening are more prevalent in this population (e.g., lack of birth control use, greater prevalence of obesity).¹ Indeed, researchers using the Rosner-Colditz risk prediction model, which quantifies reproductive risk factors for BC,² have found that SMW are at greater risk for BC compared with heterosexual women (HW) throughout the premenopausal period.³ Higher rates of BC mortality among women who cohabit with same-sex partners have also been reported.^{4,5}

Beyond increased risk, there is a small but growing body of literature that has led some researchers to suggest that

SMW (and lesbians, in particular) experience BC differently than HW. For example, lesbians have reported higher stress related to diagnosis and treatment, lower satisfaction with care delivered by physicians, and more problems with chemotherapy-induced side effects than their heterosexual counterparts.^{6,7} In the context of breast reconstruction, some SMW have reported that physicians encouraged reconstruction and failed to acknowledge other nonsurgical intervention options.⁸ There is some evidence that SMW who chose reconstruction experienced regret and difficulties, whereas SMW who opted out of reconstruction adjusted well over time.⁹ Boehmer et al. suggested that, in general, SMW focus more on the functional aspects of body image (i.e., body strength and survival vs. outward appearance and normative beauty standards) than HW and this may account for why some SMW experienced regret following reconstructive surgery (i.e., reconstruction did not improve physical functioning).⁹

There is a dearth of data related to lesbian BC patients' perspectives on breast reconstruction postmastectomy. To date, there are only two studies that have focused on breast reconstruction decision-making among SMW.^{8,9} For this study, we conducted an inductive thematic analysis of messages posted to the lesbian-specific discussion board forum found on breastcancer.org¹⁰ The benefit of this method is that we have a wider sampling frame than what we can typically accomplish with qualitative studies. In addition, our data represent discussions of breast reconstruction that were self-initiated, rather than procured in qualitative interviews. Expanding our knowledge of lesbian BC patients' perspectives on breast reconstruction could be beneficial for surgeons who provide consultation about reconstruction to BC patients and to reduce the likelihood of decisional regret among those who choose reconstructive surgery.

Methods

Procedure

The University of Wisconsin-Milwaukee's IRB determined that the present study did not qualify as human subjects research because the study did not involve intervention or interaction with human subjects and the data were considered public. We collected data from the lesbian-specific discussion board forum found on breastcancer.org; the forum was named "Lesbians with Breast Cancer."* We chose this forum because it was the largest online support venue for BC survivors and their partners and likely represents a wide range of BC patients given that there was an excess of 141,000 members at the time of data collection. Furthermore, this method of sampling enabled us to gather more data from groups that are underrepresented in academic research, such as lesbians living in rural areas and those who are less open about their sexuality.

Within the lesbian-specific forum, there were 173 topics and each topic had its own discussion board. A typical discussion board included posts from users seeking support. Often, multiple users responded to these requests and a back and forth dialogue ensued. We collected data from all 173 discussion boards found in the "Lesbians with BC" forum between the years of 2007 and 2013. Data from these discussion boards were collected and transferred into NVivo 10 qualitative software for data management.¹¹ Data from forum users who self-identified as heterosexual or bisexual were flagged and removed from our database. The remaining users were presumed to have a lesbian sexual orientation as the forum was designated for lesbians only. The present study only included data related to discussions about breast reconstruction; any post that mentioned or alluded to breast reconstruction was included. Two hundred fifty-five users posted to the lesbian-specific forum; 53 of these users discussed breast reconstruction and were included in the present analysis. We analyzed a total of 168 posts.

Analytic plan

The first and second author conducted an inductive thematic analysis¹⁰ of messages posted to the lesbian BC forum on breastcancer.org to gain a better understanding of

lesbian BC patients' perspectives on breast reconstruction. The first author recruited and trained one undergraduate research assistant (RA) and the second author, to aid in this analysis. First, she trained the RA on the basics of qualitative coding and thematic analysis. Next, they read the discussion board posts and made notes of potential themes. Then they conducted open coding until saturation of emergent codes occurred, at which point the first author developed a preliminary coding structure that combined codes into overarching themes that best depicted the data. The RA and the first author met to discuss the validity of this initial structure and then began coding posts in accordance with this structure. They had coding meetings one to two times per week for a period of ~3 months. All data were coded independently before meeting to ensure dependability of the findings. If there were discrepancies in codes, the coders discussed them until arriving at consensus. During this time, adjustments to the coding structure were made as they saw fit, particularly as it pertained to refining definitions of codes and themes. Confirmability of the codes was enhanced by acquiring alternative perspectives from the authors' research team. It was not possible to verify the findings with forum users; however, the authors attempted to increase credibility by including a coder who is queer identified and, thus, more acquainted with lesbian cultures. Limitations on transferability are discussed in the Discussion section.

Results

Our thematic analysis of discussions about breast reconstruction resulted in the identification of five themes: (1) rejecting being defined by their body image, (2) privileging sensation over appearance, (3) believing that being breastless is protective, (4) perceiving their social context as supportive of nonreconstruction, and (5) feeling pressured by social norms to undergo reconstructive surgery.

Rejecting being defined by their body image

The lesbian-specific BC forum contained discourse about embodiment and how their body images do not define them. Although posters acknowledged that breasts were considered crucial to feminine gender identity, many users denied the importance of breasts to their self-image. For instance, one woman wrote that breasts are "definitely not part of my self-identity" and another declared that she is not her breast: "I am having [a] bilateral [mastectomy] this Friday with no reconstruction. I am not my breast." There was often a sense of empowerment that came with having made the decision not to reconstruct: "I made the decision [to not get reconstruction] and I am proud of my decision. Boobs [do] not define who I am." Furthermore, many women appreciated their bodies for their utility and decided that reconstruction could get in the way of their activities (e.g., riding horses, playing soccer).

Privileging sensation over appearance

The most obvious benefit of breast reconstruction was the restoration of the "natural" breast appearance. Some, such as those who were single and seeking partners, valued appearance. However, it was more often the case that forum users were concerned about the negative consequences of having their breast(s) reconstructed, specifically as it related

*Since the date of final data collection, the forum has now been renamed to "LGBT with Breast Cancer."

to physical functioning. Breast sensation was of particular concern. Forum users discussed having a preference for sensation over appearance:

I still feel like I get hard nipples in the grocery store (even tho i have none) and I still have some nerves and feeling there....those fake boobs could have messed with that!
I was concerned that I may have no nipple or reduced nipple sensation after the symmetry surgery and I did not want to risk this.

Another woman echoed a similar sentiment about the importance of sensation: “There is nothing even the best surgeon could do to give me sensation in those perky new nipples, and that’s what I miss.”

Believing that being breastless is protective

Some women chose not to reconstruct because they viewed their breastless chest as protection from unwanted attention: “My D cups got constant attention....blech! No one looks twice at my flat chest!” Some appreciated that their lack of breasts would serve as a filter, allowing them to sift through potential romantic partners: “And anyone who wouldn’t want to get to know me if I had no breasts isn’t the kind of person I’d want to know ANYWAY! Breastless chest = instant a**hole detector!”

Perceiving their social context as supportive of nonreconstruction

A number of the forum users described existing in a social atmosphere that is supportive of variations in the appearance of breasts, including missing breasts and breasts with scars. Of particular influence was the Michigan Womyn’s Music Festival (where many chose to attend topless), which was mentioned throughout the discussion boards. Many users described their experiences at this festival and how they transformed their perspectives on breasts. One woman noted that the festival normalized breast loss:

I’ve been to women’s music festivals where topless, postmastectomy women bared their scars proudly, so in some ways I feel like I’ve had experiences where breast removal, both by choice and necessity, has kind of normalized the experience of breast loss through my community.

Beyond the anomalous Michigan Womyn’s Music Festival, the lesbian patients’ social communities, in general, were described as accepting of women regardless of gender expression. As a result, these communities normalized breast variations, including missing breasts:

I’d never been particularly attached to my tits, and I came out in a time and in a [lesbian] community where blurring gender lines was pretty well accepted and celebrated. I’ve also spent a lot of time in women’s space where women of all shapes and sizes have been topless, and some of those women had mastectomies, single, double, and it was a normal part of the landscape.

Feeling pressured by social norms to undergo reconstructive surgery

Some forum users discussed the multitude of ways they felt pressured to reconstruct their breasts, despite the fact

that reconstruction did not align with their values. This pressure appeared to be a function of heteronormative and transphobic social norms. Indeed, some users were concerned about being misidentified as transgender postmastectomy: “The last thing I would ever want [post-mastectomy] is for someone to think I was transitioning [to become male].”

Another user reflected:

It didn’t bother me when people called me sir, what bothered me was thinking that when they realized I wasn’t a guy, they’d wonder if I had the mastectomies as part of transitioning [to become male]. Nobody ever directly asked me if I was trying to transition, but I suspected they were wondering it all the time.

A desire to adhere to gender norms and avoid being perceived as transgender may have indirectly pressured some users into receiving reconstruction.

Pressure from surgeons also seemed to represent hegemonic attitudes about the importance of women keeping their breasts. In one instance, such pressure resulted in a surgery that was later regretted:

I went with immediate reconstruction based solely on the pressure of my surgeon and the fear she put in my head that my partner, [who], while agreeing with my decision not to reconstruct, may actually just be telling me what I [wanted to] hear. Having been in a previous relationship where that was a huge issue, I worried that might be the case this time as well. Honestly, [my reconstructed breasts] have presented more problems than not doing [reconstruction] could ever have caused.

At other times, the pressure from surgeons took a more indirect form: “At first, it sounded like reconstruction was the normal course I had to take.” Forum users found that their doctors were often surprised by their decisions not to reconstruct and sometimes, surgeons would go as far as failing to acknowledge the option to decline reconstruction: “When I was faced with all these decisions (I did unilateral, with implant reconstruction), none of my doctors even raised the possibility of going unreconstructed.”

Discussion

Our thematic analysis of postings about breast reconstruction on a lesbian-centric BC survivor forum resulted in the identification of five themes: (1) rejecting being defined by their body image, (2) privileging sensation over appearance, (3) believing that being breastless is protective, (4) perceiving their social context as supportive of nonreconstruction, and (5) feeling pressured by social norms to undergo reconstructive surgery. The first three themes appear to be related to breast reconstruction decision-making and an overall rejection of the surgery. The finding that many users of this lesbian-specific BC forum avoid defining themselves by their body image is consistent with previous research findings and supports the notion that SMW appear to focus on the functionality of their bodies over appearance.⁹ For instance, those who espoused a preference for functionality discussed declining breast reconstruction because of a fear that surgery would reduce sensation in their breasts. In addition, some forum users discussed added benefits of being breastless, a finding that has not yet been represented in

previous literature. That is, these users viewed their breastless chest as protection from unwanted attention from heterosexual men and from potential partners who they deemed to be superficial.

The latter two themes centered on the role of social contexts in supporting or rejecting patients' decisions about receiving or forgoing breast reconstruction surgery. A desire to adhere to gender norms and avoid being perceived as transgender may have indirectly pressured users to elect reconstruction. In addition, a number of forum users reported feeling pressure from their surgeons to consent to reconstruction, which is consistent with previous findings.^{8,12} Often, breast reconstruction was presented as normative, and in some cases, surgeons directly pressured their patients to reconstruct because they viewed reconstruction as in their patients' best interests. In contrast, many users perceived their lesbian communities to be supportive of nonreconstruction. A prominent point of reference was the Michigan Womyn's Music Festival, which largely represented lesbian feminist ideals, including a celebration of all bodies.¹³ Thus, breast reconstruction appears to be value laden, as has been suggested by Boehmer et al.⁹

Our findings have important implications for patient care. Given the pervasiveness of postings that were against normative reconstruction, oncologists have a responsibility to recognize that breast reconstruction is value laden. They should examine their biases and present multiple treatment options, including those that do not involve reconstructive breast surgery. Even within the consultation room, surgeons could display photos of different breasts (including partial mastectomies) to normalize the various choices a patient could make. Although our suggestions are patient focused, providers have much to gain from an orientation in which she or he communicates openness with respect to patient decision-making, given that patients who feel heard and who make a decision that the provider supports and respects will be more satisfied with their care.¹⁴

To date, this study is one of three studies to explore perspectives on breast reconstruction among lesbian BC patients, and our methods have enabled us to gather data from individuals who post to a public, lesbian-specific BC survivor forum. Notably, our data represent discussions that were self-initiated, rather than procured within the context of in-person interviews. This is an important distinction, as our findings are without observation biases and likely represent a wide range of individuals, including those who are unwilling or unable to participate in research studies. Our analysis resulted in the identification of several unique findings (i.e., believing being breastless is protective, perceiving their social context as supportive of nonreconstruction), which extends the literature on breast reconstruction decision-making among a group of BC patients that has largely been neglected. In addition, some users expressed fears of being falsely identified as transgender postmastectomy. We discussed the desire to avoid being perceived as transgender as a possible indirect pressure to adhere to gender norms and, thus, choose reconstruction. This is also a novel finding of our study. Although our analysis has yielded important information about lesbian BC patients' perspectives on breast reconstruction, it is not without limitations.

The context in which the data were collected needs to be taken into consideration. We collected data from a lesbian-

specific online support forum; however, we had no way of verifying that the individuals posting to these discussion boards were in fact lesbians with BC. In addition, the forum data may be more representative of those patients who are highly educated and affluent; according to the U.S. Census Bureau 2013 American Community Survey, these groups have increased Internet use and computer ownership.¹⁵ Given the method of data collection, we were not able to ask clarifying questions about what was written in the posts. Therefore, some of the data collected were uninterpretable, but may have been relevant to our study. A qualitative interview may be more advantageous than discussion forum posts, in this regard. The presumed frankness of Internet posts and lack of observation biases may counter this limitation. Furthermore, the discussion posts were not written in direct response to our research question. Therefore, users were uninfluenced by our inquiry, as they could be in an interview. Conversely, interviews might have allowed for more nuanced understandings of lesbian BC patients' attitudes toward breast reconstruction. Finally, another consideration for the interpretation of our findings is that the discussion boards from which we collected data spanned several years (2007–2013). As such, the data from the earlier years may be less applicable to the present experiences of lesbians who are living with BC.

A key finding from this analysis was the rejection of breast reconstruction among individuals posting to a lesbian-specific online BC forum. However, there were nuances that we were unable to explore within the scope of our study, such as the intersection between gender expression and lesbian sexual orientation in relation to this attitude. Indeed, gender expression has been a moderating factor in the experiences of lesbians, especially with respect to substance abuse¹⁶ and discrimination in the healthcare context.¹⁷ Examining perspectives on breast reconstruction among lesbian patients with varying gender presentations could reveal instances where breast reconstruction is desired instead of rejected. In addition, the finding that lesbians' social contexts are supportive of nonreconstruction suggests that those patients who are less connected to lesbian communities might be more likely to choose to reconstruct. Historically, lesbian communities have strong ties with feminist activism, as is demonstrated by the frequently mentioned, feminist-oriented Michigan Womyn's Music Festival.¹³ Indeed, our sample consisted of individuals who sought out a lesbian-specific discussion forum; therefore, our findings may better represent lesbians who value lesbian communities and, thus, are more likely to be exposed to feminist values that support nonreconstruction, as a result.

Conclusions

We need to learn more about lesbian BC survivors' attitudes toward breast reconstruction and their experiences managing such discussions within the healthcare context. It would be useful to survey a representative sample of lesbian-identified women who have been diagnosed with BC to determine whether the rejection of breast reconstruction is as pervasive as it appeared in this discussion forum. Research related to healthcare provider attitudes and communication about reconstruction is also warranted. For instance, researchers should study the attitudes that providers have

about reconstruction and whether these attitudes are grounded in heterosexist beliefs. Armed with that knowledge, surgeons would be better equipped to identify and alter behavior that invariably results in their patients feeling pressured to reconstruct.

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Author Disclosure Statement

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