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Restoring wholeness: Women's embodied experiences in considering post-mastectomy delayed breast reconstruction

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Abstract: This qualitative inquiry reports on the embodied experience of women with breast cancer considering post-mastectomy delayed breast reconstruction (DBR). In a pilot randomized controlled trial evaluating an educational workshop on decision-making about DBR, a purposeful sample of eight women participated in telephone semi-structured interviews. The concept of embodiment guided thematic analysis. The decision whether to undergo DBR involved four embodiment-related themes: living with an altered body, losing a sense of self, taking charge to reclaim the body and self, and rebuilding the body and self. Embodiment thus played a significant role in women's decision-making. Other psychosocial factors, however, may compete with embodiment motivations. Healthcare providers can help support women to see breast reconstruction as a legitimate means to restore their body and sense of self.

Subjects: Health and Social Care; Medical Social Work; Mental Health/Clinical Social Work; Social Work Practice; Medicine, Dentistry, Nursing & Allied Health

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PUBLIC INTEREST STATEMENT

The decision to have or not have reconstructive breast surgery following mastectomy for breast cancer is personal and influenced by many psychological, emotional, and social factors. Mastectomy can affect a woman's sense of who she is and how she feels about her body. For some, breast reconstruction is a way to restore the lost breast and more importantly, their sense of self. This study examined whether self-concept played a role in the decision-making process in women who had mastectomy and were considering DBR. Findings indicate that the decision to have breast reconstruction was not motivated by vanity, but by the strong desire to restore one's sense of body and self. For some of the women who elected not to have the surgery, body image concerns figured less prominently in their sense of self than their social roles and responsibilities.

Keywords: breast cancer; breast reconstruction; embodiment; body image; treatment decision-making

1. Introduction

With improved breast cancer treatments and longer survival rates, psychosocial well-being and quality of life have become key adjustment outcomes in long-term breast cancer survivorship. The negative impacts of mastectomy on body image and self-presentation in breast cancer, however, have been documented well in the literature (Sun, Ang, Ang, & Lopez, 2017). Poor body image and body dissatisfaction can lead to psychosocial distress and poor self-concept (Chen, Liao, Chen, Chan, & Chen, 2012; Fingeret et al., 2014; Miller, Schnur, Weinberger-Litman, & Montgomery, 2014; Przewdziecki et al., 2013; Rosenberg et al., 2013). Breast reconstruction can help to restore the breast mound and thereby improve psychosocial well-being, body image, and self-concept (Teo et al., 2016). Utilization of breast reconstruction, either immediately after mastectomy or as a delayed procedure, has increased due to improved breast cancer survival rates and surgical reconstruction procedures (Jagsi et al., 2014; Metcalfe et al., 2012). Making the decision to have or not have delayed breast reconstruction (DBR), however, is influenced by numerous factors. One factor that is central to self-experience but that has not received much attention is the role of *embodiment*, one's experience of the body not just as a physiological object but as a core phenomenological facet of self-experience (Merleau-Ponty, 1974). In the present qualitative inquiry, we investigated whether embodiment-related factors were involved in the decision-making process in women who had mastectomy and were referred for a consultation concerning DBR.

Mastectomy as a treatment for breast cancer can affect a woman's valuation of her body and sense of self (Denford, Harcourt, Rubin, & Pusic, 2011; Rowland & Metcalfe, 2014). Body image concerns are common (Boquiren et al., 2016; Buki, Reich, & Lehardy, 2016; Fang, Shu, & Chang, 2013; Fingeret et al., 2014; Rosenberg et al., 2013) and can include significant distress over scars and reduced sense of attractiveness (Fang et al., 2013). Some women are uncomfortable wearing revealing clothing, experience difficulty finding suitable clothing, and avoid related leisure activities (e.g., going to a swimming pool) (Fang, Balneaves, & Shu, 2010; Kornblith & Ligibel, 2003). Further, women often feel unbalanced (Fang et al., 2013) and less than whole or asymmetrical (Crouch & McKenzie, 2000; Thomas-MacLean, 2005) and view themselves as disfigured, imperfect (Brunet, Sabiston, & Burke, 2013), and visually disharmonized (Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010).

Breast reconstruction is an elective restorative surgery, involving the use of implants, autologous tissue, or a combination of these two methods, and can be done immediately after a mastectomy surgery or as a delayed procedure (Fallbjörk, Frejeus, & Rasmussen, 2012; Zhong et al., 2016). DBR can be done months or years post-mastectomy if desired (Zhong et al., 2016). Making the decision whether to have breast reconstruction, though, is a complex process influenced by numerous factors including age, education, ethnicity, socioeconomic status, access to plastic surgeons, risks and benefits associated with various surgical options, costs, distance to the hospital, and personal preferences and values (Brennan & Spillane, 2013; Manne et al., 2016; Sherman et al., 2016). To date, studies have focused on the use of decision aids to facilitate decision-making (Causarano et al., 2014; Manne et al., 2016; Sherman et al., 2016), on psychosocial predictors to evaluate the uptake of breast reconstruction (Metcalfe et al., 2017; Zhong et al., 2016), and on women's motivations to pursue breast reconstruction (Metcalfe et al., 2017).

Little attention has focused on the role embodiment in women's decision-making concerning breast reconstruction. Central to embodiment is the belief that people are always bodily in the world; rather than having a *physical* body, we are embodied. It assumes the intersection of the body, self, and social interactions in the formation of human experience (Merleau-Ponty, 1974), with body image as part of this process (Mock, 1993). It sees the body as meaningful and relational acquiring images and feelings concerning the body, not simply as a biological object (Lende & Lachiondo, 2009). However, embodiment is a critical concept in this population because women's

thoughts, feelings, and behaviors concerning their breasts and cancer experiences involving the breasts are grounded in bodily experience (Meier, Schnall, Schwarz, & Bargh, 2012), as well as in the societal importance and meanings placed on the female body as a whole and on missing parts (Crompvoets, 2006). Non-conforming physical appearances (i.e., a missing breast) can draw attention to the body and may disrupt social interactions, leaving women feeling uneasy, stigmatized, and alienated from their bodies (Ucok, 2005). The distress of living with an altered body, an embodied loss, can remind women that they are neither living up to socially constructed standards of femininity, sexual attractiveness, womanliness, and nurturance that the female breast symbolizes (Mock, 1993) nor upholding their public status as “real” women with two breasts (Crompvoets, 2006; Kasper, 1995). Mastectomy alters women’s embodiment experiences (Piot-Ziegler et al., 2010). As such, for women who are considering DBR, how they experience their altered bodies is an important factor in deciding about DBR as an option to restore their bodies (Crompvoets, 2006).

The literature suggests that, in deciding about breast reconstruction, women may face conflicting motivations. In an earlier study, Reaby (1998) reported that women did not decide to have breast reconstruction for unrealistic reasons (e.g., to improve marital relationships) but to redress their sense of damaged femininity and body image and their desire to achieve psychological wholeness. Similarly, Spector, Mayer, Knafl, and Pusic (2011) found that breast reconstruction allowed women to move forward from their breast cancer experience. However, women may be anxious that their body image concerns will not be understood or accepted by their husbands or family members (Freysteinson et al., 2012; Loaring, Larkin, Shaw, & Flowers, 2015; Zimmermann, Scott, & Heinrichs, 2010). They may worry about being seen as vain or having an additional procedure that others perceive to be unnecessary. Consequently, women have reported guilt and shame about having body image concerns and failing to move beyond breast cancer (Fallbjörk et al., 2012; Fingeret, 2010).

The present qualitative inquiry was part of a pilot randomized controlled trial to assess the feasibility and efficacy of a pre-consultation educational group workshop on the decision-making process for DBR post-mastectomy (Causarano et al., 2014). A pilot is a small-scale study carried out to test the feasibility (whether planned study procedures can be conducted successfully) and acceptability (whether intended participants accept or tolerate study procedures, including randomization and the intended intervention) of the proposed larger-scale study (Thabane et al., 2010). We undertook a hermeneutic (interpretative) inquiry, with a focus on embodiment, to gain a deeper understanding of eight breast cancer patients’ experiences with decision-making about delayed reconstruction within the personal and social context of living with altered bodies. Merleau-Ponty’s (1974) concept of embodiment provided the theoretical lens to understand participants’ decision-making process.

2. Methods

2.1. Participants and procedure

The mixed-method methodology (Platt et al., 2013) and quantitative results of the pilot randomized trial have been published in detail elsewhere (Causarano et al., 2014). The pilot trial was conducted at a tertiary cancer center in Ontario, Canada, and received approval from the University Health Network’s Research Ethics Board (REB#11-1027-CE). Written informed consent was obtained from all participants for both the quantitative and qualitative components. The qualitative component involved telephone interviews, audio-taped, using a semi-structured questionnaire created for the trial. Telephone interviews are a well-accepted and cost-effective approach to data collection (Irvine, Drew, & Sainsbury, 2010; Novick, 2008; Tausig & Freeman, 1988). Data collected from telephone interviews can be as rich, vivid, detailed and of high quality as that collected from in-person interviews (Novick, 2008). The telephone-interview strategy was selected based on several factors: unavailability of participants for in-person interviews (i.e., if a participant decides not to have reconstruction, she will not be returning to the hospital; if she decides to have the surgery, there could be a substantial

delay before the participant returns to the hospital and can participate in the interview); costs; distance and travel time for a research coordinator to go to participants' homes or for them to come to the hospital for the interview; and participants' personal (e.g., child care) and professional (e.g., work) commitments that may hinder their ability to come to the hospital for the interview.

For the pilot trial, women were recruited based on the following inclusion criteria: (1) had a breast cancer diagnosis; (2) had a mastectomy; (3) referred to one of three plastics surgeons (co-authors SH, AO, or TZ) for an initial DBR consultation (no breast revision or nipple reconstruction); (4) over the age of 18; and (5) able to read and speak English. Those who agreed to participate in the trial were randomized to receive the group psychoeducational workshop (intervention group) delivered by a multidisciplinary team (a plastic surgeon, a nurse specialist, a social worker, and two peer survivors who had breast reconstruction), or routine education (initial surgical consultation) delivered by plastic surgeons who were co-investigators (SH, AO, and TZ) (control group). The women in the intervention group were invited to participate in a telephone interview post-intervention to explore in depth their lived experiences with the decision-making process about DBR and their satisfaction with the workshop. Of those who agreed to be interviewed, purposeful sampling to maximize variation was used to select interviewees from each of the three plastic surgeons' ambulatory clinics, at different surgical stages, and across decision-making outcomes (had reconstruction, decided to have reconstruction, decided not to have reconstruction, were undecided).

Given the study team's extensive clinical knowledge of this population, a sample size of eight women was deemed sufficient to offer variation in embodied experiences underlying decision-making about DBR and clarify discrepancies between the intervention as intended and how intervention participants experienced it. The sample size falls within recommendations for phenomenological inquiries (Mason, 2010). Furthermore, several study characteristics have been identified as factors that increase information power in qualitative inquiries and thus decrease the number of participants required (Malterud, Siersma, & Guassora, 2016): (1) the specificity of our study aim (to examine in depth the role of embodiment-related changes in decision-making about DBR) and target sample (women who had had mastectomy and were referred for consultation about DBR); and (2) application of a theoretical perspective (the concept of embodiment and its role in body image, sense of self, and well-being) to our analytic approach (Malterud et al., 2016). Achieving saturation was not the primary sampling guideline for this in-depth qualitative inquiry because of the quantitative-driven nature of the larger pilot study (Morse & Niehaus, 2009).

The research coordinator (co-author NC) was trained to conduct interviews and coding by the research team's qualitative researcher (first author TC), who had a background in phenomenological hermeneutic inquiry. TC conducted the first two interviews with NC observing, followed by debriefings to ensure consistency in responding to non-visual cues (i.e., how to deal with silence). NC conducted the remaining six interviews. Interviews lasted about 1 h, were scheduled post-intervention to individuals' convenience, and were audio-recorded. A semi-structured telephone questionnaire was developed to solicit data from interviewees about their decision-making experiences regarding breast reconstruction. Questions included the following: What factored into their decision to consider breast reconstruction; what was their preference for decision-making; how important was it for them to share the decision-making with their plastic surgeons; were they supported by their surgeons in making the decision; did they experience decisional conflict; and what did breast reconstruction mean to them. On average, women were interviewed 7 weeks after the intervention (range = 3–12 weeks post-intervention).

2.2. Data analysis

Interviews were transcribed verbatim for analysis. Both NC and TC read every transcription against the audiotapes for transcription accuracy. We conducted an inductive thematic analysis, with a

hermeneutic focus of describing and interpreting meanings and identifying the emerging theme of embodiment. Nvivo 10.0 software was used for data management.

NC individually coded all transcripts line-by-line and collapsed them into initial themes. TC individually coded two randomly selected transcripts to corroborate the initial themes. She also reviewed all extracted statements, as well as all themes and interpretations, from the eight transcripts to verify coding accuracy and provided additional interpretation of the coded data provided as necessary. Interpretation was verified through regular debriefings (NC, TC). An iterative process was undertaken involving an initial reading of the text to understand the global understanding of the narrative, followed by line-by-line reading, coding, and interpretation (Benner, 1994).

In interpretative inquiries, the multiple stages of interpretation that allow patterns to emerge, discussion of how interpretations arose from the data, and the interpretive process itself are critical ways to ensure rigor (Koch, 1995). Rigor is further achieved in qualitative studies by ensuring credibility, dependability, transferability, and confirmability (Guba & Lincoln, 1985). To address credibility, data were derived through a participant-driven data collection process using the women's exact words, a constant search for commonalities and differences, and team debriefings (NC, TC). To ensure dependability, interviewers engaged in constant reflexivity and maintained memos and an audit trail to enhance transparency and reproducibility. Reflexivity involved NC and TC acknowledging their clinical knowledge of the population and verifying with each other to minimize any biasing impact of their knowledge on data interpretation or new insights; TC further acknowledged her clinical practice with this group and her hermeneutic focus embedded in the interpretative process. The interviewer also introduced concepts expressed from previous interviews to the next so as to validate commonalities or variation in experiences and triangulate the data. Interpretation of the data was accomplished by researchers (NC, TC) engaging in constant reflexivity and maintaining reflexive journals. To ensure transferability, probe questions (e.g., "Could you please tell me more about that?") were used to achieve rich experiential descriptions until participants reported that no further new information. Women's exact words or sentences were used to support interpretations. Finally, to ensure confirmability, NC and TC engaged in reflexivity throughout data analysis and maintained an audit trail to enhance reproducibility (Braun & Clarke, 2006).

3. Results

Forty-one participants were enrolled in the trial: 21 were randomized to the intervention group, and 20 to the control group. One woman in the intervention group did not receive her assigned treatment in full, citing that she was no longer interested in participating and did not want to be contacted for the interview. Of the 20 women who completed the intervention, we purposefully sampled eight of these women to undergo the telephone interview. The eight women agreed to be interviewed, citing altruistic reasons (e.g., to help other women in deciding to have or not have DBR) for their participation. Demographic and clinical characteristics of the eight women are presented in Table 1. The median number of years since mastectomy was just over 1 year. At the time of their interview, two women had breast reconstruction. Of the remaining six women, three decided to have DBR, one decided not to have the procedure, and two remained undecided.

Codes were organized into four themes related to embodiment: (1) living with an altered body; (2) losing a sense of self; (3) taking charge to reclaim the body and self; and (4) rebuilding the body and self.

3.1. *Living with an altered body*

The narratives of the eight women reflected their experiences of living with an embodied loss. Body image was a significant concern for all the women in their decision-making process about DBR. They recalled the invasiveness of the disease, their struggle with losing their breast, and their negative feelings associated with their altered bodies. Words used to describe feelings included

Table 1. Demographic and medical characteristics of eight interviewed women

Characteristics	Median	Range
Time since mastectomy (years)	1.13	0.4–10.4
Age (years)	48.5	42–50
	n	%
Marital status		
Single	1	12.5
Married/living with partner	7	87.5
Education		
University or higher	8	100.0
Employment		
Employed full-time	5	62.5
Unemployed/seeking employment	1	12.5
On medical leave/disability	2	25.0
Income		
<\$60,000	1	12.5
≥\$60,000	6	75.0
Missing	1	12.5
Ethnicity		
Caucasian	7	87.5
Non-Caucasian	1	12.5
Surgical reconstruction status at interview		
Pre-reconstruction	6	75.0
Post-reconstruction	2	25.0
Pre-reconstruction decision-making at interview (n = 6)		
Waiting for surgery	1	17.0
Decided to have reconstruction	2	33.0
Decided not to have reconstruction	1	17.0
Undecided	2	33.0

shocked, devastated, horrified, frightened, bothered unattractive, ugly, and less than whole. They described their body as disfigured, deformed, broken, disproportioned, scarred, and concaved. Seven of the eight women interviewed were self-conscious about their physical bodies and body image in public and intimate situations. The one woman who was not concerned about her physical appearance and decided not to have breast reconstruction attributed this to the small size of her breasts; she could easily camouflage the loss of one breast by wearing a prosthesis. However, most women worried about their breast prosthesis falling out or others noticing that they had no breast mound. One woman reported losing sexual interest after mastectomy and wondered whether women need two breasts to be sexually active.

All women reported the limited choice of clothing was the most negative impact of their mastectomy. This limitation significantly diminished their feelings of femininity and attractiveness and sense of bodily normality:

I feel disproportioned. I feel like when I put, even with the prosthetics, clothes on, I just don't feel right. And I can't wear the same clothes. Like I used to be able to wear strapless [or] spaghetti straps. I used to be able to wear low cut tops, all that kind of stuff. You can't do that with prosthetics or with no breasts. (ID#7, age 50)

One woman reported that she avoided going out because her clothes did not look right on her even with the prosthesis:

I've been wearing baggy clothes from all kinds...not even caring anymore. I think I avoided going out and doing things more [and] that would've affected family and friends. (ID#4, age 45)

For the two women who had breast reconstruction and the three women who were waiting to have it, one of the reasons that they decided to have the surgical procedure was because it would restore the varied clothing options they once enjoyed. When presented with the fact that other participants had indicated limited clothing options as a reason to undergo procedure, the two women who remain undecided about the surgical procedure said the limited clothing options was not a factor in their decision-making.

3.2. Losing a sense of self

In all of the women, their negative perceptions of their altered bodies affected their sense of who they were and how they thought and felt about themselves:

It's awful. It's absolutely horrifying. I had this flat chest on the top...it just implodes you as a human being in terms of how you feel about yourself. It's funny 'cause when you're younger you strive to be different but when you're older, all you want to do is be like everyone else, be normal. (ID#8, age 48)

Their decision-making process also included concerns about being seen as "vain" by their family and friends. Some women thus experienced shame and embarrassment about having body image concerns. Four women reported being confronted with external attitudes that discouraged consideration of breast reconstruction: they were told that they should be glad they were still alive rather than worry about their physical appearance, or they were made to feel that breast reconstruction was an unnecessary procedure.

3.3. Taking charge to reclaim the body and self

All women interviewed were proactive in seeking out information on breast reconstruction from various resources. This suggested a strong desire to take charge to reclaim their body and self. All eight women reported that their families supported their desire to consider breast reconstruction and left the decision to them. This was consistent with the women's decision-making preferences, as they wanted to make their own choice in taking back their bodies. Breast reconstruction was seen as a means of regaining control over their body and re-establishing their sense of self, as well as looking normal to others. However, not all of them were prepared immediately to undergo the surgical procedure. They spent considerable time researching breast reconstruction, as they wanted to make an informed decision. They sought information from the Internet and attended an annual community breast reconstruction event (BRA Day) to hear from plastic surgeons about reconstructive surgery options and meet other survivors who had breast reconstruction. They agreed to attend the psychoeducational workshop (the study intervention) to learn more about breast reconstruction and have the opportunity to ask specific questions related to their condition.

I was a very, you know, reasonably educated consumer. So I'd already done quite a bit of research...I went to the BRA day thing. Like I've been really...doing a lot of research on [reconstruction]...[I searched] the Internet and [read] the literature-booklets you provided and gotten through the hospital. (ID#2, age 49)

Further, they considered various factors associated with breast reconstruction, including their personal preferences (i.e., autologous tissue vs. implant procedure) and values, the number of procedures involved, the risks of complications and infections, the length of hospital stay and recovery period, the impact on family and responsibilities (e.g., child care), and the necessity of further absence from work. Six women reported feeling "confident" and "empowered" about

making an informed decision, including the decision not to have breast reconstruction. One woman said that the information gained confirmed what she knew already, mainly that breast reconstruction was “lots of work” and a “long process and there [is] much involved in undertaking [the procedure]” (ID#6, ag2 49).

3.4. Rebuilding the body and self

For all women, breast reconstruction meant that they could improve their body image and, more importantly, rebuild their bodies and their sense of being “normal” and “whole” women. Having a reconstructed breast also meant that they could wear certain clothes:

[Reconstruction] is not about vanity but about having more clothing choices...able to wear what I want to wear and feel comfortable with what I'm wearing...think that I need it for my own personal feelings to feel whole. (ID#5, age 49)

The two women who had breast reconstruction were pleased with the outcome and reported improved self-confidence and femininity. They felt a sense of closure and moving forward, “a new beginning.” Another reason one woman decided to have the procedure was so that her daughters would have “positive images about female shape” (ID#8, age 48). One woman further decided to have the procedure to fight back against breast cancer:

Cancer took my breasts, I'm going to fight it by getting new ones...I think when I've got breasts again and I look the way I want to look again...then I'll feel like I've battled it and won. (ID#7, age 50)

One woman summarized the significance of having breast reconstruction in this way: “It is about wanting to have a normal body and not have any missing parts” (ID#6, age 49).

Not all women decided to have reconstruction because of competing concerns. One woman who decided against breast reconstruction concluded that the complications associated with the procedure, the financial burden of taking time off from work, and her child care and household responsibilities were too great:

The procedures would be drawn out, like over six months. And then, you know, the recovery would be several weeks, right? So, to me, that's just a long time...I just can't be out of commission because I've got a four-year-old...I cannot be, not at 100% functional. (ID#1, age 42)

Two women were undecided because of the various factors associated with the procedure. One of these women reported that while her marital separation and future dating opportunities made her realize the importance of having a breast, she was unsure whether the recovery time required and the potential risks were worth it:

I want to have it done but I'm a little bit nervous about having it done and you know, I'm healthy and I don't want to open myself back up again, and I don't want the recovery time, but is it worth it? (ID#6, age 49)

4. Discussion

To our knowledge, our qualitative inquiry is one of the few studies to elucidate the role of embodiment in women's decision-making process about DBR post-mastectomy. Four themes related to embodiment emerged: (1) living with an altered body; (2) losing a sense of self; (3) taking charge to reclaim the body and self; and (4) rebuilding the body and self. Hence, decision-making about breast reconstruction is not simply an issue of replacing the breast mound. The themes illustrate the multi-faceted nature of breast cancer patients' embodiment-related changes relating to decision-making about DBR. Furthermore, they suggest that the sense of self is inherently intertwined with the bodily state, lending support to the concept of embodiment and its importance in treatment decision-making in this clinical population. The decision to have breast

reconstruction was not motivated by vanity but by the desire to restore one's sense of body and self. Decision-making, though, was further influenced by a variety of psychosocial factors that might compete with any desire to redress the embodied loss.

All of the women interviewed were distressed about losing their breasts and reported difficulties living with an altered body and self-image. Metcalfe et al. (2017) similarly reported that high levels of psychosocial distress and body image concerns motivated some women to pursue DBR. Given that the breast is an important aspect of women's sense of femininity and linked intrinsically to their identity, sexuality, and sense of self (Crompvoets, 2006; Przedziecki et al., 2013), the loss of this body part can result in negative changes in body image. In turn, this can disrupt emotional well-being and self-concept (Helms, O'Hea, & Corso, 2008; Sun et al., 2017) and motivate decisions to have breast reconstruction to restore both the body and sense of self.

However, some women noted significant psychosocial obstacles to redressing the embodied loss and changed sense of self. They reported concerns about being perceived as vain or undergoing an unnecessary procedure and, as a result, felt guilt and shame about having body image concerns, considering delayed reconstruction, or failing to move beyond the illness experience. Other studies reported similar issues (Fallbjörk et al., 2012; Fingeret, 2010; Reaby, 1998). Alternatively, the desire to be whole and normal may underscore the societal value and meaning placed on feminine beauty and women's intact bodies and perceived pressure on women to uphold their public status as women in these regards (Crompvoets, 2006; Crouch & McKenzie, 2000; Kasper, 1995; Piot-Ziegler et al., 2010). In fact, some women may thus feel that they have little choice but to have breast reconstruction (Fallbjörk et al., 2012). These concerns highlight not only the role of social-interpersonal factors in body image and sense of self, but also important targets for assessment and intervention in the consultation process.

In the decision-making process, the women in this study were self-reportedly proactive and took charge in reclaiming their bodies. They sought information from various sources and made decisions autonomously based on consideration of the risks and time associated with the procedure and on their embodied desire to achieve a sense of wholeness and normality. Other studies have also described the proactive nature of breast cancer patients' exploration of reconstruction options (Neill, Armstrong, & Burnett, 1998) and breast reconstruction as a way for women to reclaim control over their bodies (Rubin, Klassen, Cano, Hurley, & Pusic, 2009). The high education level of the eight participants could contribute to the desire for proactive information-seeking and autonomous decision-making, however. Having husbandly support in the decision-making process was still important to the women. While many men may view breast reconstruction as unnecessary or unimportant, they are nonetheless supportive if they feel it will improve their wives' self-esteem (Rowland & Metcalfe, 2014). These men, however, report high unmet informational needs concerning how to be more involved in their wives' decision-making (Rowland & Metcalfe, 2014). Healthcare providers can suggest including husbands in their wives' consultations and facilitate couples' communication and adjustment.

For most women in this qualitative inquiry, breast reconstruction offered not only an end to prostheses and limitations in clothing options, but also, most importantly, a means to restore the body and the feeling of wholeness and normality and thereby to improve body image and self-confidence. For the two women who had DBR and the three women who decided to have DBR, the procedure provided these benefits, restoring or promising to restore their sexuality and femininity, critical facets of their sense of self, and bringing closure to their cancer experience. The two women who had reconstruction reported improved satisfaction with their body image. Other studies have also documented the primary importance of breast reconstruction in regaining a feeling of being whole and normal and fitting in (Alderman et al., 2011; Crompvoets, 2006; Denford et al., 2011; McKean, Newman, & Adair, 2013; Rubin & Tanenbaum, 2011), as well as pragmatic reasons such as avoiding wearing a breast prosthesis (Alderman et al., 2011). As observed in our study, these benefits facilitated women's capacity to move beyond cancer and resume pre-mastectomy functioning (Denford et al., 2011; Fang et al., 2013; McKean et al., 2013; Spector et al., 2011; Zhong et al., 2016).

However, potential embodiment-related benefits did not automatically translate into a decision to have breast reconstruction, as evidenced by one woman who decided against having breast reconstruction and two women who remained undecided. Besides risks and complications associated with reconstruction, psychosocial issues such as time off from work, financial burden, and family responsibilities (e.g., looking after young children) were important factors in the women's decisions. For these three women, their sense of self may be defined more by their social roles and responsibilities, than by their body image concerns. Considerations not to undergo breast reconstruction may thus be rooted in cultural and value systems that emphasize social roles and functioning (Buki et al., 2016; Fang et al., 2010; Rubin & Tanenbaum, 2011). Uncertainty, fears, and anxiety, risks associated with surgery, and time associated with breast reconstruction and recovery have been similarly reported elsewhere as factors that may conflict with any desire to rebuild the sense of self (Alderman et al., 2011; Manne et al., 2016).

5. Limitations

Our qualitative inquiry has some limitations that need to be considered. Participants were women who completed the group intervention and invited for interviews. Unfortunately, data on the number of women asked to be interviewed and their reasons for declining were not collected for the qualitative inquiry. Hence, responses might be affected to some degree by volunteer and selection biases. In addition, because medical co-investigators were involved in participants' surgical care, responses might reflect some social desirability bias. However, desirability bias was likely limited, as participants' responses included both positive and negative responses and were generally congruent with breast cancer patients' reports in clinic. The women were also assured that there were no right or wrong answers, and they were presented with the range of lived experiences reported by previous participants to normalize response disparity. Participants were mostly Caucasian, highly educated, and of higher economic status. Comparative studies are required to assess generalizability to the experiences of non-Caucasian breast cancer patients or of those from other educational and socioeconomic groupings.

Our sample size was quite small, though it was deemed adequate for this qualitative inquiry given the specific nature of our pilot study aims and sample, as well as the application of a theoretical perspective (Malterud et al., 2016). The small number of women facilitated the interviewer's rapport with participants and open and frank responding, enhancing the validity of in-depth inquiry (Crouch & McKenzie, 2006). Interview responses were generally articulate, informative, and relevant and were similar to patients' decision-making considerations observed in the co-authors' clinic practice. We also sampled women across all decision outcomes to maximize variation. Given our interpretative focus, our concern was not about generalizing findings to the general population but rather enhancing our in-depth understanding of embodiment-related meanings and their role in patients' decision-making concerning DBR – hence, the use of purposeful sampling (Malterud et al., 2016; Palinkas et al., 2015). However, our findings are only a first step toward distinguishing inherent relationships between the body and self in breast cancer and how these relationships influence treatment decision-making. Replication studies should sample a larger number of patients to response saturation, to evaluate comprehensiveness of our embodiment-related themes and elaborate upon them.

6. Implications for practice and research

Our findings suggest that it is important that healthcare providers are aware of and sensitive to the issues of women's embodiment and its disruption and assess them during consultations for reconstruction. Healthcare providers are in a unique position to instill confidence in cancer patients (Deimling, Bowman, & Wagner Louis, 2007). They can help women explore embodiment issues intrinsic to decision-making about DBR, disarm negative interpersonal or intrapersonal attitudes regarding breast reconstruction (e.g., that considering breast reconstruction reflects vanity), and thereby reduce their embarrassment or shame for considering this option. Decision aids or educational efforts employed in the decision-making process should include queries about embodiment-related concerns and point women to specific resources to help them effectively address such

concerns. Addressing such concerns might not only facilitate treatment decision-making, but also improve long-term psychosocial adjustment and quality of life in breast cancer survivors.

7. Conclusion

The decision to undergo reconstructive breast surgery following mastectomy for breast cancer is personal and multi-faceted. Our findings point to the significant role embodiment plays in women's consideration of DBR and competing medical and psychosocial considerations that may override embodiment-related concerns. The knowledge gained from this study can help broaden the understanding of women's decision-making process about DBR and stimulate much-needed research on embodiment in breast cancer treatment and breast reconstruction.

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Competing interests

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