

Clinical Correspondence

Body image perceptions among women with pre-existing physical disability who developed breast cancer: a qualitative exploration

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Dear Editor,

Introduction

Given that over 24% of women in the USA have a disability, and approximately 6% of Americans use mobility aids [1], a significant number of breast cancer survivors will likely have mobility impairments [2]. Physical disability can affect body image, and women with physical disabilities hold more negative body image perceptions than other women [3]. Body image concerns are also common among breast cancer survivors [4]. Breast cancer treatment can result in decreases in body satisfaction, potential breast disfigurement, and bodily changes [5]. Research has not examined body image among women with preceding disability and breast cancer; we thus sought to explore body image perceptions among women with chronic, pre-existing physical disability who developed early-stage breast cancer.

Methods

This research is part of a larger published study investigating diagnosis and treatment experiences of women with physical disabilities who developed early-stage breast cancer [2,6].

Participants

Participants were 20 English-speaking women who completed treatment for early-stage breast cancer before age 60 and had chronic difficulty walking or used an ambulation/wheeled mobility aid because of polio/post-

polio syndrome, spinal cord injury, cerebral palsy, multiple sclerosis, or other conditions (Table 1). Participants were identified through oncologists' patient panels and informal networks of women with disabilities [7].

Procedure

A semi-structured interview guide was developed that included questions about how disability affected treatment decision-making, including issues of body image relating to breast cancer.

The interviews occurred from December 2007 to October 2008, lasted 1–2 h and were audiotaped. Women received \$100 remuneration for participation. Institutional Review Boards at Beth Israel Deaconess Medical Center and Massachusetts General Hospital approved this study.

Data analysis

Audiotapes were transcribed and reviewed for accuracy and completeness. Two authors (K. B. S. and K. E. C.) read the interviews and determined which aspects were relevant to women's self-perceptions regarding body image. We also conducted a keyword search for each full transcript using the terms 'attractive', 'body', 'body image', 'sex', 'partner', and 'husband'. These two authors then coded all data independently with NVivo 8 (QSR International, Melbourne, Australia) and used thematic content analysis to identify major concepts [8]. At each analysis phase, the coders compared results to confirm intercoder reliability, resolving discrepancies through discussion and comparison of the raw data (final Kappa=0.98) and resolution with a third investigator (E. R. P.).

Table 1. Participant characteristics

Characteristic	N
Age at time of breast cancer	
30–39 years	3
40–49 years	7
50–59 years	10
Age at time of interview	
30–39 years	—
40–49 years	1
50–59 years	11
60–69 years	5
70 years and older	3
Race	
White	17
Other	3
Education	
High school only	2
Some college (no degree)	2
College degree	8
Postgraduate education	8
Marital status	
Married or partnered	11
Divorced	3
Widowed	1
Never married	5
Underlying disabling condition	
Polio, disabled in childhood or post-polio syndrome as adult	9
Spinal cord injury	3
Cerebral palsy	3
Multiple sclerosis	2
Other ^a	3
Mobility aid use at time of breast cancer diagnosis ^b	
Occasional use (cane, crutches, or walker)	4
Constant use (cane, crutches, or walker)	7
Manual wheelchair	3
Power wheelchair or scooter	6
Breast cancer treatment ^c	
Lumpectomy	16
Mastectomy	4
Chemotherapy	9
Radiation	13
Medication	10

^aIncludes degenerative disk disease, rheumatoid arthritis, and childhood surgical complication.

^bSome participants utilized more than one mobility aid; the aid providing the most support was counted.

^cTwo women required second surgeries because of positive margins; two women received both lumpectomy and mastectomy.

Results

Influence of body image on women's breast cancer treatment preferences

About half of the women reported that appearance concerns influenced their treatment preferences. Several women reported that their desire for breast-conserving procedures was related to concern about how treatment would affect appearance. As one participant who received lumpectomy explained, 'I think that probably I just couldn't imagine not having the breasts and being so deformed and debilitated'. One woman indicated that concern about treatment-related

appearance change influenced her desire for reconstructive surgery; she 'couldn't imagine' other women not choosing reconstruction. Another described how concern about medication-related weight gain influenced her decision to stop the medication.

Not all women, however, indicated that appearance concerns affected their treatment preferences. A few women emphasized that survival benefits outweighed appearance concerns; one described telling her clinicians, "whatever you have to do – save my life. Just save my life. I don't want to die..." even if they had to take my breast at that point, I wanted them to do whatever they had to do.'

Breast cancer treatment perspectives related to women's body image: influence of physical disability

A couple of women discussed how the potential appearance effects of breast cancer treatment were made less significant by having a disability. As one woman stated, she had 'dealt with body image change already'. Another explained her thinking as follows: 'I wore braces as a kid. My frame of reference is different. I've had deformity in my body. I've transcended my body. My body is a vessel that carries my spirit.' In contrast, two women reported that the potential appearance effects of breast cancer treatment would be even more significant because of their disability. One reported that her self-perceived disfigurement from disability made reconstruction important to pursue: '... I had dealt with the polio, my right leg is deformed and I just did not want to not have a breast.'

Breast cancer treatment preferences related to women's body image: significant other influences

Women's body image-related treatment preferences were also influenced by important others. Here, women mostly indicated that their preferences for specific procedures were influenced by either being single or having a partner who was unconcerned about potential appearance effects. One woman conveyed her partner's support regarding mastectomy with the following: 'I don't mind you only having one breast ... that body image stuff doesn't matter to me, I just want you well.' Another woman, who had a breast prophylactically removed, conveyed her acceptance with the sentiment: '... I'm not married. I might as well just be done with it and have the breast off.'

Breast cancer treatment influenced women's body image

Some women reported dissatisfaction with their appearance during and following treatment, particularly with regard to weight gain. A few women felt uninformed about how treatment would alter appearance: 'I didn't know what [the doctor] meant when he said he would have to check my lymph nodes. I didn't know it meant a seven-inch incision starting

at the top of my underarm and going all the way back and way down.' One woman reported dissatisfaction with the appearance of her breasts following treatment, stating 'I still have a sense of when I look in the mirror who I am, and this is not me. I can look better than this.'

More women, however, voiced accepting or neutral views of their body and appearance during and following treatment. One participant expressed appreciation for her breasts as a result of her cancer experience: 'I've always wanted large breasts and I never got them. Between that and there being a great possibility of losing one, I had a brand new appreciation for what I had.' Furthermore, some women were not concerned about scarring or appearance of their breasts: 'I had such a small cancer that the incision ... you can tell, but it's not anything that's that noticeable.' Notably, no spontaneous discussion occurred that linked women's body image perceptions during and following treatment to their disability.

Discussion

We explored how body image perceptions and physical disability influenced women's breast cancer experiences and treatment, as well as how such experiences influenced body image. Similar to previous research with breast cancer survivors who did not have pre-existing disability, our findings suggest that cosmetic reasons influence women's choice to pursue breast-conserving procedures (e.g., [9]). Our analyses also suggest, however, that the body image effects of breast cancer treatment vary for women with physical disabilities. Indeed, most women did not report a negative impact of treatment with regard to body image.

Although participants' mobility considerations influenced their decisions about surgical approach and chemotherapy [2], most women did not express that having a physical disability influenced their breast cancer treatment perspectives with regard to body image. While women were not necessarily probed explicitly about whether their disability influenced their body image, it appears that practical considerations may overshadow body image-related concerns. Nevertheless, a few women did express that their disability made cosmetic effects of breast cancer treatment more significant, and a few expressed that cosmetic effects were made less significant because of pre-existing disability. It thus seems that chronic disability had the potential to either strengthen women's resilience in the face of potentially appearance-altering treatment or make them more vulnerable to body image concerns. Clinicians should be aware that disability may influence women's body image in the context of breast cancer treatment and should inquire about such effects.

Our study has limitations. Because we conducted interviews after initial treatment was complete, some women were recalling experiences from years before. Our largely White, educated sample also does not represent women with physical disabilities, and not all underlying causes of physical disability were represented.

In sum, we found that women with physical disabilities have differing attitudes about the importance of body image in relation to breast cancer treatment, results that seem similar to those of research with non-disabled women undergoing breast cancer treatment. For example, Figueiredo *et al.* [10] found that about a third of their large sample of older women with breast cancer cited body image as important to their treatment decisions. This point is important to highlight, given that, despite being similar in some ways to other women, women with disabilities may experience disparities in breast cancer treatment [11]. Because women with impaired mobility might have additional practical concerns, however, and because pre-existing disability may influence body image in some women, clinicians should consider the complex factors that guide these women's breast cancer treatment decisions. At minimum, women's concerns regarding cosmetic effects should be elicited during treatment-related decisions. Involving partners and family members in treatment decisions may also help women address body image concerns related to treatment and aid in their decision-making process. Our results underscore the importance of assessing women's individual needs and concerns when diagnosed with breast cancer. Future research may consider comparing women with pre-existing physical disability who develop breast cancer to breast cancer patients without such disability to determine if and how body image perspectives differ between groups.

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Conflict of interest

The authors have declared no conflicts of interest.

Key points

- Although body image concerns are prevalent among breast cancer survivors, research has not explored body image perceptions among women with pre-existing physical disability who develop breast cancer.
- Qualitative interviews were conducted with 20 women treated for early-stage breast cancer who had chronic, pre-existing physical disability.
- Body image had a variable influence on women's breast cancer treatment preferences. In some women, body image-related treatment perspectives were influenced by disability and significant others.
- Treatment itself also variably influenced women's body image.
- Clinicians should recognize that women with physical disabilities who develop breast cancer may have body image concerns.

References

1. Centers for Disease Control and Prevention. Prevalence and most common causes of disability among adults – United States, 2005. *Morb Mortal Wkly Rep* 2009;**58**:421–426.
2. Iezzoni LI, Park ER, Kilbridge KL. Implications of mobility impairment on the diagnosis and treatment of breast cancer. *J Womens Health* 2011;**20**:45–52. DOI:10.1089/jwh.2009.1831.
3. Nosek MA, Howland C, Rintala DH, Young ME, Chanpong GF. National study of women with physical disabilities: final report. *Sex Disabil* 2001;**19**:5–40.
4. Alfano CM, Rowland JH. Recovery issues in cancer survivorship: a new challenge for supportive care. *Cancer J* 2006;**12**:432–443.
5. Helms RL, O’Hea EL, Corso M. Body image issues in women with breast cancer. *Psychol Health Med* 2008;**13**:313–325.
6. Iezzoni LI, Kilbridge K, Park ER. Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments. *Oncol Nurs Forum* 2010;**37**:711–717.
7. Kuzel AJ. Sampling in qualitative inquiry. In *Doing Qualitative Research*, Crabtree BF, Miller WL (eds.), SAGE Publications: Thousand Oaks, CA, 1992; 31–44.
8. Patton MQ. *Qualitative Evaluation and Research Methods* (2nd ed.), SAGE Publications: Thousand Oaks CA, 1990.
9. Nold RJ, Beamer RL, Helmer SD, McBoyle MF. Factors influencing a woman’s choice to undergo breast-conserving surgery versus modified radical mastectomy. *Am J Surg* 2000;**180**:413–418.
10. Figueiredo MI, Cullen J, Hwang Y-T, Rowland JH, Mandelblatt JS. Breast cancer treatment in older women: does getting what you want improve your long-term body image and mental health? *J Clin Oncol* 2004;**22**:4002–4009.
11. McCarthy EP, Ngo LH, Roetzheim RG, et al. Disparities in breast cancer treatment and survival for women with disabilities. *Ann Intern Med* 2006;**145**:637–645.